What's in a label?

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Public stigma toward people with intellectual disabilities

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A percentage! What splendid words they have; they are so scientific, so consolatory….
Once you've said 'percentage' there's nothing more to worry about.
If we had any other word … maybe we might feel more uneasy….

Fjodor Dostoevsky, Crime and punishment

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Chapter 1

General introduction

The normal and the stigmatized are not persons, but perspectives.
-- Erving Goffman

People with intellectual disabilities are challenged twofold. Not only do they face challenges due to limitations in intellectual and adaptive functioning, but also do they experience barriers in daily life that hinder them to achieve valuable life goals and limit their wellbeing (Scior et al., 2016; Scior & Werner, 2016). Intellectual disabilities (see, Textbox 1) occur with an incidence of about 1-2% of the population, which indicates that more than 150 million people worldwide (Maulik et al. 2011) and about 142.000 people in the Netherlands (www.vgn.nl/feiten-encijfers) are faced with these challenges. In the Netherlands, an increasing number of people with borderline intellectual functioning (IQ 75-80) receives support from intellectual disability services as well, and is labelled as having mild intellectual disabilities (Nouwens, Smulders, Embregts, & van Nieuwenhuizen, 2017; Woittiez, Putman, Eggink, & Ras, 2014). Although the Netherlands has relatively good resources, social policies and legislation concerning people with disabilities, people with intellectual disabilities still experience inequalities in, for example, monetary access (Emerson, 2007), access to health care (Krahn, Hammond, & Turner, 2006), access to competitive employment (Ellenkamp, Brouwers, Embregts, Joosen, & van Weeghel, 2016; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009), inclusive education (de Boer, Pijl, & Minnaert, 2011), and mainstream leisure activities (Verdonschot et al. 2009). Thus, people with intellectual disabilities experience barriers towards participation and inclusion in society (WHO [World Health Organisation], 2011). Stigmatisation toward people with intellectual disabilities is proposed as one of the main causes for this inequality that requires societal and political action (Scior et al., 2016, 2020; Trani, Bakhshi, Bellanca, Biggeri, & Marchetta, 2011; WHO, 2011).

TEXTBOX 1

According to The Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013), people are diagnosed with an intellectual disability in the case of:

- Significant limitations in intellectual functioning (i.e., IQ <70), that impact their
- Adaptive functioning in the conceptual (e.g., language, math), practical (e.g., money management), and social (e.g., empathy) domain
- The limitations must have their onset during the developmental period

Intellectual disability can be classified into the groups: Mild, Moderate, Severe, and Profound intellectual disability (Carr & O'Reilly, 2007).

People with intellectual disabilities report stigmatisation, -the experience of a devalued identity-, in various ways (see, next paragraph for a conceptualisation of stigma). For instance, inaccessibility of buildings, information, and public transport is widely apparent and can be seen as a very visible form of stigmatisation and hindrance to wellbeing (Tøssebro, 2016). But also less visible forms of stigmatisation are reported. For example,

employment is valued by people with intellectual disabilities (Miller, Cooper, Cook, & Petch, 2008; Voermans, Taminiau, Giesbers, & Embregts, in press). However, negative attitudes of employers (Skelton & Moore, 1999) or non-disabled colleagues (Li, 2004), and experiences of stigmatisation (Voermans et al., in press) are reported and found to influence their opportunities for competitive employment (Zappella, 2015). Moreover, people with intellectual disabilities report people in the general public talking down to them, looking at them in a funny way, or making them feel embarrassed (Abbot & McConkey, 2006; Ali, King, Strydom, & Hassiotis, 2015; Ali, Strydom, Hassiotis, Williams, & King, 2008). Due to their awareness of belonging to a stigmatised group (Beart, Hardy, & Buchan, 2005), people with mild or moderate intellectual disabilities may have difficulty to establish or preserve positive social identities (i.e., self-stigma) – which may have negative consequences for their mental health, aspirations, and sense of belonging (Ali et al., 2015; Giesbers, Hendriks, Jahoda, Hastings, & Embregts, 2018; Jahoda & Markova, 2004; Jahoda, Wilson, Stalker, & Cairney, 2010). Finally, in recent years, important steps have been taken to include the voices of people with intellectual disabilities themselves in for example research (Bigby, Frawley, & Ramcharan, 2014; Embregts, 2018; Embregts, Taminiau, Heerkens, Schippers, & van Hove, 2018; Frankena et al., 2019) However, on a level of structural stigma, people with intellectual disabilities continue to be of low priority in government policies and programmes and are often not well represented in the disability rights movement (Scior et al. 2016).

TEXTBOX 2a

"Nancy: I've been trying to find a permanent job somewhere for a long time, because I've also been working hard on building my future and those kinds of things, you know, but I always tell my job coach, I say that if I can only work a certain number of months each time, and then it's not renewed, you know, then I always say, 'But how? How do I build up a pension?' (Voermans et al., in press)

In the field of intellectual disabilities, awareness of stigma and stigma research has only recently started to attract attention (Ditchman et al., 2013; Scior & Werner, 2016). This recent attention in research is demonstrated by the fact that different review studies on stigma were conducted in the past ten years; namely on public stigma (Scior, 2011), self- and courtesy stigma (see, textbox 3) (Ali, Hassiotis, Strydom, & King, 2012), and measurement of stigma in the field of intellectual disabilities (Werner, Corrigan, Ditchman, & Sokol, 2012). All these review studies report a lack of studies into stigmatisation of people with intellectual disabilities.

The upcoming consideration of stigmatisation seems to accord with the history of deinstitutionalization. That is, in the first half of the nineteenth century people with intellectual disabilities were often living in institutions located outside urban areas. Therefore, there was little contact between them and the general public. In the period of deinstitutionalization (starting in the 60/70's), people with disabilities started to move

into the community. Nowadays, 92% of Dutch people with mild or moderate intellectual disabilities are living in a community setting (Meulenkamp et al., 2015). As a result, in case of increased opportunities for contact between people with and without intellectual disabilities, opportunities to feel and experience the stigmatisation also increase (Cooney, Jahoda, Gumley, & Knott, 2006). Moreover, although people with intellectual disabilities prefer community living over living in institutions, they face problems in the community such as loneliness, lack of meaningful work, and lack of choice in decisions that affect their own lives (Bekkema, de Veer, Wagemans, Hertogh, & Francke, 2015; Bekkema, de Veer, Wagemans, Hertogh, & Francke, 2014; Johnson & Traustadottir, 2005). Thus, similar to what has been reported for people with mental illness (Brummel, 2017; Gardner, Filia, Killackey, & Cotton, 2019), physical integration into the community does not automatically lead to a situation in which people with intellectual disabilities are fully accepted and have equal opportunities to reach valuable life goals (see textbox 2a/b). Stigmatisation is a major reason for experiencing these problems. It is, therefore, not without reason that the United Nations convention on the rights of persons with disabilities (CRPD), states non-discrimination, awareness-raising, and action to combat stigma as important goals within their statement. The Dutch government ratified the CRPD in 2016. Thus, there is an urgent need to further examine and explain experiences of stigmatisation of people with intellectual disabilities as well as to challenge intellectual disabilities' stigma (Scior et al., 2016).

TEXTBOX 2b

"Listen, do you know what the problem is with our society? People who have nothing to do with support services. I live here in care and that is something that works for me. When you live in care, in an organization for people with disabilities, then it is harder to become part of a group. Because those people [in the broader society] have their own lives, they grew up together, and then I come along. That is not appreciated. Because they already have a good thing going with their friends and you are not needed. And that sounds harsh (Giesbers et al., 2018).

CONCEPTUALISATION OF STIGMA: A SOCIAL-PSYCHOLOGICAL FRAMEWORK

Stigma refers to the experience of a devalued identity in a certain social context due to an attribute that is discounted (Crocker, Major, & Steele, 1998). Originally, the word stigma is derived from Greek and literally means stain or brand. In Christian tradition it referred to the marks corresponding to those left on Christ's body by the crucifixion. Nowadays, in a prominent elaborate conceptualisation, stigmatisation entails labelling, negative evaluation of the label (i.e., stereotypes), endorsement of the negative label (i.e., prejudice), which leads to status loss followed by discrimination in a context of power inequality (Link & Phelan, 2001). Or, stated briefly, stigma entails the process whereby negative cognitions (stereotypes), lead to negative emotions (prejudice), followed by a behaviour response to prejudice (discrimination) (Corrigan & Watson 2002). The concept of stigma was introduced in the social sciences by Erving Goffman (1963) and was elaborated on from sociology, clinical psychology as well as social psychology.

FIGURE 1 | Social-psychological process of stigma: cognitions, emotions, behavioral responses.

In this thesis we have examined stigmatisation from a social-psychological framework. That is, processes are described that may explain the behaviour of people from the general public towards people with intellectual disability. Social psychology thereby mediates between psychological approaches (describing intrapsychic experiences of stigmatisation) and sociological approaches (describing processes on the level of society like norms and cultural rules and values) (van 't Veer, Sercu, & Van Weeghel, 2016). Social psychology relates stigma to people's cognitive, emotional and behavioural reactions towards people with intellectual disabilities (Dovidio, Major, & Crocker, 2000) (see Figure 1). For example, beliefs that people have about the cause of intellectual disabilities (e.g., biomedical or environmental) are related to different emotions (e.g., compassion or fear) which are related to people's willingness to have social contact with people with intellectual disabilities (Scior, Connolly, & Williams, 2013).

TEXTBOX 3

Stigma can be found in various forms (Van Weeghel, Pijnenborg, Van 't Veer, & Kienhorst, 2016). In this thesis we focus on public stigma. The different forms of stigma are as follows:

Collective level	
Public stigma	The reaction that the general public has towards people with intellectual disabilities including negative cognitions (e.g. stereotypes) and negative emotions (e.g. prejudice), followed by discriminatory behaviour (Corrigan & Watson, 2002; Scior, 2011)
Structural stigma	Social norms, policies, and procedures that (un-)intentionally have stigmatising effects, for example by restricting opportunities for individuals with intellectual disabilities (Corrigan, Markowits, & Watson, 2004)
Individual level	
Self-stigma	The prejudice that people with intellectual disabilities turn against themselves, the internalization of public stigma by which people believe that they will be devalued (Ali et al., 2012)
Courtesy stigma	Stigma on those who are closely related to the person with intellectual disabilities, for example family members being teased, abused, or blamed for the persons disability (Ali et al., 2012).
Affiliate stigma	Self-stigmatisation in family members, leading to negative self-evaluations, negative emotions and withdrawal from society (Mak & Cheung, 2008).

For other minority groups, such as ethnic minorities and people with mental illness, social-psychological stigma research has been more prevalent. For example, for ethnic minorities it has been clearly demonstrated that stereotypical traits are used to explain the status quo of unequal treatment at the individual, group, and system level (Biernat & Dovidio, 2000; Corrigan et al., 2001; Jost & Hamilton, 2005). Also, for people with mental illness negative stereotypes have been shown to provoke discrimination, which appears as avoidance or withholding help (Angermeyer & Matschinger, 2005; Corrigan et al., 2003; Corrigan, Green, Lundin, Kubiak, & Penn, 2001; Reavley & Jorm, 2011). Similar effects may be expected for people with intellectual disabilities. For example, stigmatising attitudes may relate to less adherence to the value of inclusion (Gilmore et al., 2003), to avoidance of people with an intellectual disability (Werner, 2015), or to withholding choices in life (Bekkema et al., 2015). Yet, so far evidence for such effects is minimal (Ditchman et al., 2013).

THE CASE FOR STIGMA RESEARCH

To date, in the field of intellectual disabilities, the neutral term 'attitudes' dominates research and discussions while attention for the concept of 'stigma' including notions like stereotypes, prejudice and discrimination is only recent and still limited (Werner et al., 2012; Werner, 2015). There is a substantial amount of overlap between the concepts of stigma and attitudes, for example in the triad of cognitive, emotional, and behavioural components (Werner, 2016). Therefore, we need to explain the reason why we do not address the more often used concept of 'neutral' attitudes, but specifically address the negative phenomenon stigma. We describe two reasons. First, attitudes do not capture the full stigma process from labelling to discrimination including public, self-, and structural stigma (see also, Textbox 3; Werner, 2016). Second, within 'attitude-research' there is a dominant focus on positive phenomena such as social inclusion, empowerment, or rights (Ditchman, Easton, Batchos, Rafajko, & Shah, 2017; Horner-Johnson et al. 2015; Venema, Otten, & Vlaskamp 2016). Daly and Silver (2008) have demonstrated in their review study that studying 'positive' phenomena like (attitudes towards) social inclusion promotes research into consequences such as quality of life and wellbeing. Yet, research into negative phenomena such as stigma promotes research into the causes of these phenomena (e.g., attributions, lack of familiarity) (Blundell, Das, Potts, & Scior, 2016; Scior & Furnham 2016). Thereby, research on stigma can especially inform us about causes of inequality and exclusion and thereby informing interventions based on working mechanisms that can explain inequality and exclusion. Examining stigma thus is an essential addition to attitude research in the quest for improving social inclusion and empowerment.

THE STIGMA PARADOX: DILEMMA OF DIFFERENCE

Before turning to the focus of this thesis, we want to address an essential notion about stigma and stigma research. This concerns the paradoxical fact that when addressing

stigma, people with intellectual disabilities are presented as a distinct group from the general population. This can be considered as stressing the difference between 'them and us' and thereby emphasising the stigma that we in fact want to address. More specifically, there is the widespread idea that stigma might mean 'treating people differently'. This is indirectly illustrated by Tuffrey-Wijne and colleagues (2014) within a study in a hospital setting, where: *"There was widespread reluctance among staff to identify and flag patients with intellectual disabilities. This seemed to stem mostly from a belief that 'equal treatment' means 'the same treatment'".* Thus, there is the idea that addressing stigma might be stigmatising in itself because people with intellectual disabilities are labelled as a group; and that labelling and treating people differently is stigmatising (Tuffrey-Wijne et al., 2014).

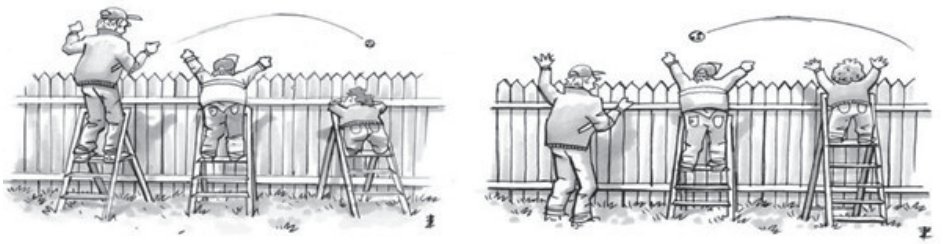

FIGURE 2 | Withholding people from differential treatment can be stigmatising (van der Klink, 2019)**.**

However, when addressing stigma in a context of social justice or specifically a capabilities approach (Corrigan, Watson, Byrne, & Davis, 2005; Pelleboer-Gunnink, Brummel, van Weeghel, & Embregts, 2018; Pelleboer-Gunnink, Van Weeghel, & Embregts, 2014; Terzi, 2004, 2005) the basic belief is that all people are in essence different and thus need different resources to achieve similar levels of wellbeing (Sen, 1979; 2009). As illustrated in Figure 2, withholding people from differential treatment could even lead to situations of discrimination.

For example, for people with intellectual disabilities, withholding additional support in accessing healthcare, or coaching in the use of digital banking (Hayes & Martin, 2007), or appropriate support regarding inclusive education (Reindal, 2010) might lead to a situation of discrimination and exclusion. In this context of social justice, treating people equally and reducing stigma thus means: providing people with different resources according to their needs. This relates to what Terzi (2005) framed as the dilemma of difference (Terzi 2005). *The dilemma of difference consists in the seemingly unavoidable choice between, on the one hand, identifying "people with intellectual disabilities"*(inserted by author) *differences in order to provide for them differentially, with the risk of labelling and dividing, and, on the other hand, accentuating 'sameness' and offering common provision, with the risk of not making available what is relevant to, and needed by, individual people*. Thus, although addressing stigma might seem paradoxical in that people are labelled and presented as a group, when discussing stigma in a context of social justice, labelling people to provide them with different

resources is in fact needed to prevent discrimination. Labelling as a way to examine stigma and explore its mechanisms thereby serves a purpose of reducing inequality.

GENERAL PUBLIC: FOCUS OF THE PRESENT THESIS

Grounded in a social psychological perspective, in this thesis we focused on the perceiver's side of stigmatisation, that is, the perspective of the one who is stigmatising (i.e., public stigma) instead of the one who is the target of stigmatisation (i.e., self- or experienced stigma, affiliate or courtesy-stigma) (See also textbox 3; Dovidio, Major, & Crocker, 2000). As was stated before, it has been clearly demonstrated that people with intellectual disabilities are aware and experience consequences of their stigmatised identity (see also, Textbox 4), such as difficulty to maintain a positive sense of self, symptoms of anxiety and depression, and a lower quality of life (Ali et al., 2015; Chen & Shu 2012; Jahoda et al., 2010). However, there is limited clarity about the perceivers' side of stigmatisation and the processes that can explain and describe stigma (Ditchman et al., 2013). That is, stigma is a process that comprises elements such as labelling, negative evaluation of the label (i.e., stereotypes), endorsement of the negative label (i.e., prejudice), and discrimination (Link & Phelan, 2001). To date, there is little knowledge about these separate elements of public stigma and therefore there is not sufficient clarity yet about the full process of public stigma concerning people with intellectual disabilities. For example, the question concerning the nature of the set of stereotypes that is attributed to people with intellectual disabilities remains unsettled so far (Ditchman et al., 2013). In recent years, Werner was the first to test a conceptual model of stigmatisation of people with intellectual disabilities by the general public including stereotypes, emotions, and discrimination (Werner 2015). However, as Werner (2015) states herself, future studies are needed to examine what aspects of stigma were missing in this first model. Thus, more research is needed into elements of public stigma concerning people with intellectual disabilities.

TEXTBOX 4

"Sharon (17 years) talked in the interviews about a keen sense of difference and her fear of people "looking at you if you're daft (stupid) (…) "How come I'm different from my brothers and I'm stupid, and how come my nephew can count and I can't and he's seven" Jahoda et al. (2010).

In addition to a focus on the perceivers' perspective (general public), in this thesis, our focus was on the self-report of stigmatisation and not on actual daily interactions. In the Netherlands, in recent years, three doctoral dissertations have focused on actual daily interactions between people with and without intellectual disabilities in neighbourhoods (van Alphen, 2011; Bos, 2016; Bredewold, 2014). Two dissertations were grounded in a social inclusion perspective. These theses qualitatively described limited contact between the general public and people with intellectual disabilities, as well as experiences of uncomfortableness and incomprehension of the general public towards interactions

with people with intellectual disabilities (Bos 2016; Bredewold 2014). Van Alphen (2011) used a social psychological approach with both qualitative and quantitative studies and concluded that the general public's relationship with neighbours with intellectual disabilities cannot be simplified in terms of either stigmatising or accepting attitudes. Rather, more research is needed in the underlying cognitions and emotions that influence neighbour contact. In this thesis we further explore those underlying cognitions, emotions and behavioural intentions on the population level.

In this thesis, we have also focused on two subgroups within the general public that can play a key role in people's opportunities for inclusion within healthcare and society, namely mainstream health professionals, and care providers who provide specialist services to people with intellectual disabilities. That is, especially within mainstream healthcare, experiences of stigma and discrimination by people with intellectual disabilities have been well described and reported (Heslop et al., 2014; Krahn, Hammond, & Turner, 2006; O'Leary, Cooper, & Hughes-McCormack, 2018). Because health is a dominant issue in people's life, health professionals are important stakeholders when examining stigma. Stigma of health professionals toward people with intellectual disabilities may influence professionals' effort to support inclusion in mainstream healthcare services (Tuffrey-Wijne et al., 2014). Moreover, care providers in intellectual disability services are key agents who support people to step out of the social and economic margins of society (Stevens & Harris, 2017) and to cope with stigmatisation (Craig, Craig, Withers, Hatton, & Limb, 2002). Moreover, people with intellectual disabilities themselves indicate that care providers in intellectual disability services are an essential and valuable element of their social network (Giesbers et al., 2018; Van Asselt-Goverts, Embregts, & Hendriks, 2013; 2015). Yet, within psychiatry also care providers have been found to hold stigmatising attitudes and thereby restrict opportunities for patients (Lauber, Nordt, Braunschweig, & Rössler, 2006; Van Boekel, Brouwers, Van Weeghel, & Garretsen, 2013). The same may hold true for care providers in the field of intellectual disabilities. Given their important role in supporting people with intellectual disabilities to cope with stigmatisation this is especially relevant to examine. Thus for these two groups within the general public, we examined whether indications of public stigma regarding people with intellectual disabilities could be found.

PRESENT STUDY

In this thesis we thus wanted to make a contribution to the understanding of the stigma toward people with intellectual disabilities. To explore 'what's in a label' when it concerns people with intellectual disabilities. All chapters focus on the perceiver's perspective (i.e., the one who stigmatises) of people with intellectual disabilities.

Part 1: The Dutch general public's views about people with intellectual disabilities.
The second chapter reports on the outcomes of a large population survey. The focus was on the stereotypes that are apparent within the general public about people with

intellectual disabilities. Also the relationship between stereotypes and often reported measures of discrimination and familiarity with intellectual disabilities was examined. The third chapter presents outcomes of the same population survey and explores the role of general public's levels of familiarity with people with intellectual disabilities, its relationship with stigma, and the role of emotions in this relationship. The fourth chapter reports on a small scale study that further explored stereotypes. We examined which assigned characteristics distinguish people with intellectual disabilities from the general public according to the general public.

Part 2: Indications of stigma among health professionals and care providers.
In the second part of the thesis, a broad review study was conducted into stigma by two subgroups of the general public. Chapter five presents the results on research into stigmatising attitudes of mainstream health professionals toward people with intellectual disabilities. Chapter six presents the results wherein studies were explored that can provide indications of care providers' stigmatisation of people with intellectual disabilities.

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Chapter 2

Public stigmatisation of people with intellectual disabilities: A mixed-method population survey into stereotypes and their relationship with familiarity and discrimination

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ABSTRACT

Purpose

Stigmatisation can negatively affect opportunities for people with intellectual disabilities to participate in society. Stereotyping, a first step in the process of stigmatisation, has been insufficiently explored for people with intellectual disabilities. This study examined the general public's set of stereotypes that is saliently attributed to people with intellectual disabilities as well as the relationship of these stereotypes with discriminatory intentions and familiarity.

Materials and methods

A mixed-method cross-sectional survey within a representative sample of the Dutch population (n = 892) was used. Stereotypes were analysed with factor analysis of a trait-rating scale, and qualitative analysis of an open-ended question. The relationship between stereotypes and discrimination as well as familiarity with people with intellectual disabilities was explored through multivariate analyses.

Results and conclusions

Four stereotype-factors appeared: "friendly", "in need of help", "unintelligent", and "nuisance". Stereotypes in the "nuisance" factor seemed unimportant due to their infrequent report in the open-ended question. "Friendly", "in need of help", "unintelligent" were found to be salient stereotypes of people with intellectual disabilities due to their frequent report. The stereotypes did not relate to high levels of explicit discrimination. Yet due to the both positive and negative valence of the stereotypes, subtle forms of discrimination may be expected such as limited opportunities for choice and self- determination. This may affect opportunities for rehabilitation and might be challenged by protest-components within anti-stigma efforts.

Implications for rehabilitation

- There is currently sparse input for anti-stigma campaigns regarding people with intellectual disabilities.
- Anti-stigma interventions may benefit from adopting protest elements: education of the general public about inequalities that are experienced by people with intellectual disabilities.
- Especially support staff should be informed about the experienced and/or anticipated stigma of people with intellectual disabilities.
- As a way of opposing stigma, support staff should empower people for example by conducting strategies to disclose their (intellectual) disabilities.
- People with intellectual disabilities can challenge stigma by learning to tell a positive narrative on the lives they lead, using their strengths and coping with their limitations.

The United Nations' Convention on the Rights of Persons with Disabilities declares full and active participation in society as a fundamental right of persons with disabilities (United Nations, 2006). People with intellectual disabilities, however, experience disadvantages in various areas of life that limit their possibilities for rehabilitation and participation in society. These can be barriers concerning access to mainstream healthcare (Iacono, Bigby, Unsworth, Douglas, & Fitzpatrick, 2014; Krahn, Hammond, & Turner, 2006), entrance to competitive employment (Li, 2004; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009), taking up family roles (Meppelder, Hodes, Kef, & Schuengel, 2015), making independent/individual housing choices (Bekkema et al., 2015; Bowey, McGlaughlin, & Saul, 2005), or participation in mainstream leisure activities (Verdonschot et al., 2009).

Stigma is one of the main reasons for these limited opportunities to people with intellectual disabilities (Abbott & McConkey, 2006; Arvidsson, Granlund, & Thyberg, 2008; Scior et al., 2016). For example, negative attitudes of employers may pose a challenge for people to gain competitive employment (Skelton & Moore, 1999). Moreover, people in the general public using condescending language or making them feel embarrassed may have negative effects (Abbott & McConkey, 2006; Ali et al., 2015). People with intellectual disabilities experience difficulty establishing or preserving positive social identities due to their awareness of belonging to a stigmatised group (Jahoda & Markova, 2004; Jahoda et al., 2010). This may have negative consequences for both their mental health and their aspirations concerning participation (Jahoda & Markova, 2004; Jahoda et al., 2010).

Stigmatisation refers to people's experience of a devalued identity because of certain (assumed) distinguishing characteristics (Dovidio et al., 2000; Goffman, 1963) in a context where the power situation allows stigma to occur (Link & Phelan, 2001). The present study focused on processes of stigma in the general public, referred to as public stigma. From a social-psychological perspective, public stigma originates from negative cognitions followed by negative affective reactions and consequent discriminatory behaviour (Dovidio et al., 2000). Hence, public stigmatisation is a triadic process whereby stereotypes are a first, cognitive component that refer to a specific set of characteristics that is assumed to exist among people with intellectual disabilities (Biernat & Dovidio, 2000). These stereotypes can be followed by prejudice (i.e., affective reaction) and discrimination (i.e., behaviour) (Corrigan & Watson, 2002).

Although an increasing number of studies try to disentangle processes of stigma, research into stereotypes, prejudice, and discrimination of people with intellectual disabilities is still scarce (Scior, 2011). Within the field of intellectual disabilities, the neutral term 'attitudes' dominates research; attention to the negative term 'stigma' is yet limited (e.g., (Werner, 2015; Werner et al., 2012). Notwithstanding the fact that attitudes and stigma are often intermingled, attitudes do not cover the full stigma construct (Werner, 2016). A focus on stigma is important because addressing a negative phenomenon (i.e., stigma) promotes research into its causes, while studying positive phenomena such as 'attitudes towards participation' promotes research into consequences (Daly & Silver, 2008; Ditchman et al.,

2013). In this way, research into stigma enhances our understanding about the causes of inequality, as opposed to exploring the consequences of participation. Moreover, the ultimate reason for conducting research into stigmatisation of people with intellectual disabilities is to find effective ways to contest the stigma. In order to do so, there needs to be evidence about the determinants of stigma that should be addressed in interventions.

Because stereotypes are the initial cognitive component of stigma, it is essential to document the general public's salient stereotypes of intellectual disabilities (Ditchman et al., 2013). Currently, the question of the nature of this set of stereotypes remains unsettled (Ditchman et al., 2013; Scior, 2011). Preliminary available studies that examined stereotypes of intellectual disabilities used an inadequate sample (i.e., small sample of university students; (McCaughey & Strohmer, 2005) or studied stereotypes regarding a sub-group of people with intellectual disabilities (i.e., people with Down syndrome; Gilmore, Campbell, & Cuskelly, 2003). More recently, Werner (2015) studied stereotypes of intellectual disabilities, with a seven-item stereotype trait-rating scale in a selective sample of the general public. She based the scale on an attitude scale for people with physical disabilities and pilot interviews with 6 people from the general public (Werner, 2015). This indicates that evidence about the stereotypes of people with intellectual disabilities can still benefit from additional research.

In addition to exploring the stereotypes, it is important to determine how stereotypes can result in discriminatory treatment. For other minority groups, such as ethnic minorities, it has been clearly demonstrated that stereotypes are used to explain discrimination at the individual, group, and system level (Biernat & Dovidio, 2000; Corrigan, Green, Lundin, Kubiak, & Penn, 2001; Jost & Hamilton, 2005). Also, for people with mental illness, negative stereotypes have been shown to provoke discrimination, expressed as avoidance, withholding help, or imposing restrictions (Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003; Corrigan et al., 2001; Reavley & Jorm, 2011; van Boekel, Brouwers, van Weeghel, & Garretsen, 2013). For people with intellectual disabilities, studies into stereotypes and discrimination are scarce, but similar effects may be expected. For example, stereotypes may relate to less adherence to the value of inclusion (Gilmore et al., 2003) or to avoidance of people with intellectual disabilities (Werner, 2015).

Furthermore, positive contact and familiarity with people with intellectual disabilities, or with any other minority group, is seen as an important factor in tackling stigma (Allport, 1954; Blundell et al., 2016; Clement et al., 2012; Scior, 2011). Especially the closeness of a relationship (i.e., familiarity) has been found particularly important when studying stigma of people with intellectual disabilities (Blundell et al., 2016).

RESEARCH AIMS AND QUESTIONS

Given the limited evidence about salient stereotypes of people with intellectual disabilities, this paper aimed to extend existing studies by using different sources to initiate a trait-rating scale of stereotypes, and using an open-ended question to (a) explore any stereotypes complementary to the trait-rating scale as well as to (b) address the salience of the stereotypes, in a representative sample of the general population. Moreover, the paper aimed to extend the limited knowledge about the association between familiarity with people with intellectual disabilities and stereotypes, as well as between discrimination and stereotypes. Specifically, higher levels of familiarity/closeness with people with intellectual disabilities were hypothesised to be related to weaker stereotypes. The aims of this study lead to the following questions:

- What are the main stereotypes of intellectual disabilities among the Dutch general public?
- Is the strength of the stereotypes related to levels of discrimination (i.e., social distance and withholding help) towards people with intellectual disabilities?
- Is the level of familiarity with individuals with intellectual disabilities related to the strength of the stereotypes?

METHOD

Procedure

In February 2015, responses from a nationally representative sample were collected in the Netherlands using the - Longitudinal Internet Studies for the Social Sciences - panel. The panel was based on a true probability sample of households drawn from the population register and was developed in cooperation with Statistics Netherlands. The panel consists of 5,600 households with 8,735 panel members age 16 or older. Full information about the panel can be found at www.lissdata.nl. The panel is administered by CentERdata (Tilburg University, The Netherlands), a research institute specialising in quantitative data collection. CentERdata abide by the Dutch 'protection of personal data' act (Wet Bescherming Persoonsgegevens), consistent with and derived from European law (Directive 95/46/EC).

During recruitment, participants consented to become panel members and participate in monthly internet surveys. Participants are rewarded for each completed questionnaire. People not included in the original sample could not otherwise participate. Potential participants without a computer or internet connection were provided with the necessary devices to participate. For this study, a questionnaire was sent to a random selection of 1,093 panel members. A response rate of 81.6% (n = 892) was obtained. Five participants (0.5%) did not complete the questionnaire.

Participants

A total of 892 members of the Dutch general public participated in this cross-sectional survey. In the sample, 50.8% were female and 49.2% male participants; 90.5% reported a Caucasian background, 6.0% reported a non-Caucasian background or did not report on background (3.5%). Reported education concerned low (25.7%), middle (38.1%), or higher (33.7%) education, or was missing (0.2%). Reported age groups concerned < 20 years (4.9%), 20-40 years (26.2%), 40-65 years (43.8%), 65-80 years (22.1%), or >80 years of age (2.9%). Demographics of the study sample are similar to demographics within the Dutch population according to Statistics Netherlands, yet with a slight underrepresentation of participants with a non-Caucasian background (i.e., 12.1% within the Dutch population).

Measures

Stereotypes: Trait-rating scale

A unipolar trait-rating format was used to enable participants to respond to 18 stereotypes as found in literature and a pilot study. Participants were asked to rate their agreement (ranging from 1 = completely disagree to 5 = completely agree) about statements describing people with intellectual disabilities; for example, "People with intellectual disabilities are happy." Eleven stereotype-items were extracted from intellectual disabilities literature (Eayrs, Ellis, & Jones, 1993; Gilmore et al., 2003; McCaughey & Strohmer, 2005). In a pilot study among a convenience sample of the general public (n = 90), the present authors corroborated these stereotypes. People were asked to note five words in answer to the question: "What comes first to your mind when you think about people with intellectual disabilities?" All 11 stereotypes that emerged in the literature were also found within the pilot study and thus included within the scale. To ensure similar meanings across languages, a bilingual speaker of Dutch and English was involved in translating the items from relevant literature in English to Dutch language. To verify the completeness of the scale, seven items (i.e., 'are to be trusted', 'can be aggressive', 'neglect themselves', 'are able to work in a paid position', 'give nuisance', 'are criminal', 'are intelligent') were derived from previous studies into stereotypes towards people with mental illness within the Dutch population (van Boekel, Brouwers, Weeghel, & Garretsen, 2015; van 't Veer, Kraan, Drosseart, & Modde, 2006).

Stereotypes: Open-ended question

Using an open-ended question, participants were asked to type their answer to the following question in a text box: "Finally, can you give us, in a few sentences, a characterisation of people with intellectual disabilities? What comes first to your mind when you think about people with intellectual disabilities?" This question was asked for two reasons: first, to determine whether complementary stereotypes were apparent that were not yet described in the literature (i.e., to ask whether the trait-rating scale is exhaustive and what items might need to be added). Note that in an open-ended question, participants are not restrained by the particular stereotypes provided by the

researcher. The second reason was to assess the frequency with which stereotypes are reported to examine the salience of the stereotypes (Haddock & Zanna, 1998). Previous studies have demonstrated that participants are adequate in producing words and phrases that represent valid stereotypes about a group (Eagly, Mladinic, & Otto, 1994; Haddock & Zanna, 1998).

Familiarity: Level of Contact Report

Familiarity was measured by the Level of Contact Report (Holmes, Corrigan, Williams, Canar, & Kubiak, 1999) and refers to varying degrees of closeness that the general public has with people with intellectual disabilities (Corrigan et al., 2001; Holmes et al., 1999). Participants were asked to check all of the situations on a 12-item list that best depicted their exposure to people with intellectual disabilities. Example items are: (1) "I have worked with a person who had an intellectual disability at my place of employment" and (2) "I have never observed a person that I was aware had an intellectual disability." The index of familiarity was the rank score of the closest situation indicated by the participant. Because of the non-normal distribution of the rank scores, three categories were created based on the content of the items, indicating low familiarity (rank-items 1–4; $n = 273$), average familiarity – not in private life (rank-items 5–8; $n = 338$), and high familiarity – in private life (rank-items 9–12; $n = 281$).

Discrimination: Social distance

Social distance is frequently used as an indicator for discrimination and refers to the tendency of people to avoid contact with individuals with certain conditions (Whatley, 1959). To measure social distance, participants were asked to rate how willing they would be with regard to the following interactions with a person with intellectual disabilities (1 = definitely not to 5 = definitely): (1) to move next door to the person, (2) to spend an evening socialising with the person, (3) to make friends with the person, (4) to start working closely with the person, and 5) to have the person marry into the family. These items were replicated from a previous study (Link et al., 1999). The internal reliability of the scale is good (Cronbach's $\alpha = .84$). Items were recoded so that a higher score indicates a greater desire for social distance.

Discrimination: Withholding help

Helping behaviour, another frequently used indicator for discrimination, refers to people's tendency to provide or to avoid helping people with certain conditions (P. Corrigan et al., 2003). Participants were asked to what degree they would agree with a set of statements (1 = totally disagree to 5 = totally agree). The statements were: (1) "If I were an employer, I would interview someone with an intellectual disability for a job", (2) "I would share a car pool with someone with an intellectual disability each day", (3) "If I were a landlord, I probably would rent an apartment to someone with an intellectual disability", and (4) "I am certain I would help someone with an intellectual disability." Items were replicated

from a previous study in the field of psychiatry (2003) (Corrigan et al., 2003). The internal reliability of the scale is satisfactory (Cronbach's α = .79).

Analyses

The analysis consisted of four steps. First, exploratory Principal Axis Factoring was used to explore whether factors of stereotypes could be found in the trait-rating scale. The factorability of the correlation matrix was examined and the likely number of factors was assessed based on scree-plot and Eigenvalues > 1 (Tabachnick & Fidell, 2007). Based on the assumption that the stereotype factors are to some extent inter-correlated and not independent, an oblimin rotation with Kaiser Normalisation and delta 0 was used. Factor loadings of .40 and greater were interpreted (Field, 2009). The test reliability of the factors was inspected by examining the Cronbach's alpha (α), McDonald's omega (ω), greatest lower bound, and average inter-item correlations (Dunn, Baguley, & Brunsden, 2014; Sijtsma, 2009). Mean scores were calculated for the items categorised within the stereotype factors and used in subsequent analyses.

Second, multivariate analysis of covariance was used to assess the differences among categories of familiarity on the mean scores of the stereotype factors. Age, gender, and education level were added as covariates. Effect sizes ($\eta 2$) for univariate between subjects' effects were interpreted as: 0–.10 small effect, .10–.30 modest effect, .30–.50 moderate effect, and > .50 large effect. Post-hoc pairwise comparisons were conducted using Bonferroni correction to correct for the Type I error rate.

Third, hierarchical linear regression with a stepwise approach was used to predict the levels of discrimination. In step 1, the demographic covariates of gender, age, and education level were added. In addition, in step 2, familiarity was added, and in step 3, the stereotype factor mean scores were added as predictors.

Lastly, responses to the open-ended question were analysed qualitatively by using the program Atlas.ti, version 7.5. For all responses, quotations were divided in single quotation-units by the first author. Two researchers then independently categorised the single quotations (n = 1227) in three steps. First, quotations that were literally similar to items under one of the factors were coded as belonging to that factor. Second, quotations that were synonyms of items under one of the factors were labelled as belonging to that factor. In the first two steps we thus used a selective-deductive approach whereby quotations were labelled on the basis of factors from the trait rating scale. In the third step, we followed an open-inductive approach to categorise the remaining quotations (n = 565) into meaningful categories. In all three steps, the coding and categorisation were discussed until consensus was reached, after which a third researcher checked the coding and provided critical feedback. Following, all categories were discussed with all authors. The categories referring to stereotypes of people with intellectual disabilities (i.e., characteristics; n = 9 categories) are included in this article. Other categories (n = 7) referring to values (e.g., attitudes towards inclusion) or to knowledge (e.g., causes of

intellectual disabilities) are not discussed in this article, but can be obtained from the first author. Finally, to get an impression about the salience of the different stereotypes that were reported, the frequency of quotations referring to the stereotypes was reported.

RESULTS

Prior to Exploratory Factor Analysis, the data were screened to explore whether the normal distribution assumption was satisfied. As the kurtosis (max. = 1.249) and skewness (max. = –0.563) of the observed variables were within the range of ± 7 and ± 2, respectively, normal distribution was assumed (Kim, 2013).

Exploratory Factor Analysis: Exploring stereotype factors

Several significant correlations between stereotype-items upheld the factorability of the observed correlation matrix (NB matrix can be retrieved from the first author). Additionally, a Kaiser-Meyer-Olkin's measure of sampling adequacy value of .814 and an anti-image correlation matrix with mostly small values among the off-diagonal elements supported this conclusion (Tabachnick & Fidell, 2007).

Next, Table 1 presents the mean scores, standard deviations, test reliabilities, and results of Principal Axis Factoring with oblimin rotation of the stereotype items. Four factors with an Eigenvalue > 1 were extracted, which was supported by visual inspection of the scree plot. Items with a factor loading ≥ .40 were selected (Field, 2009), resulting in a model that explained 54.45% of the total variance. Over 30% of the people scored the neutral option (do not agree/do not disagree) for all items except for 'criminal' and 'vulnerable'. Based on the 'Cronbach's alpha if item deleted' and 'McDonald's omega if item deleted', deleting the items 'affectionate' (α increased from .723 to .746 and ω from .740 to .754) and 'childlike' (α increased from .677 to .687 and ω from .685 to .690) would improve test reliabilities. However, due to the minor increase in test reliabilities, the items were retained.

Concerning the first factor (Friendly), the majority of participants indicated that people with intellectual disabilities are friendly, sociable, and happy. For items in this factor, more than a third to almost two-thirds of participants (37.3%–59.9%) agreed with these statements, whereas a small number (1.5%–6.5%) disagreed with these items. Regarding the second factor (In need of help), most participants indicated that people with intellectual disabilities are in need of help, vulnerable, and have difficulty functioning in society (53.7%–80.8%), and a small percentage of participants disagreed with the items (1.6%–5.6%). The third factor (Give Nuisance) consists of items that mainly described negative traits. In general, people did not find these items characteristic for the studied population (35.4%–79.1% disagreed and 1.0%–8.1% agreed), except for the item 'childlike' (14.5% disagreed and 35.1% agreed). Finally, the factor Unintelligent describes the difficulty with learning experienced by people with intellectual disabilities (i.e., the item 'intelligent' was re-coded during calculation of the mean score). More than half (57.2%) of the participants

agreed that people with intellectual disabilities have difficulty learning, but for the item 'intelligent', most participants scored the neutral option (60%). The relationships between the mean factor scores suggest that the factors represent sufficiently distinct stereotypes. That is inter-correlations between the factors were respectively .093, -.441, -.102, -.003, .275, .035.

TABLE 1 | Descriptive statistics of stereotypes and structure matrix of Principal Axis Factoring with direct oblimin rotation (*n* =888).

Item	Factor loading	*h*	*M (SD)*	Agree (%)	Neutral (%)	Disagree (%)
Friendly						
(α = .746; ω = .754; glb = .780; avg_iic = .427)						
… are friendly	.745	.567	3.67 (0.66)	59.9	38.6	1.5
… are sociable	.683	.497	3.40 (0.62)	40.1	57.1	2.8
… are happy	.651	.435	3.48 (0.61)	44.8	53.7	1.5
… are to be trusted	.479	.296	3.34 (0.70)	37.3	56.2	6.5
… are affectionate	.425	.226	3.44 (0.68)	44.3	51.7	4.1
In need of help						
(α = .571; ω = .582; glb = .610; avg_iic = .306)						
… are in need of help	.599	.366	3.53 (0.69)	53.7	41.3	5.0
… have difficulty functioning in society	.553	.379	3.52 (0.68)	53.7	40.7	5.6
… are vulnerable	.542	.341	3.95 (0.63)	80.8	19.3	1.6
Give nuisance						
(α = .687 ω = .690; glb = .698; avg_iic = .356)						
… give nuisance	.644	.428	2.49 (0.74)	5.0	47.9	47.1
… are sad	.597	.344	2.29 (0.81)	6.7	30.2	63.1
… neglect themselves	.574	.367	2.69 (0.70)	8.1	56.5	35.4
… are criminal	.547	.424	1.84 (0.78)	1.0	19.9	79.1
… are childlike	.437	.328	3.19 (0.76)	35.1	50.3	14.5
Unintelligent (α = .57; avg_icc 273)						
… are intelligent	.718	.555	2.81 (0.72)	11.1	60.0	27.9
… have difficulty learning	-.446	.269	3.58 (0.70)	57.2	38.6	4.2
Remaining items						
… are able to work in a paid position	-		3.56 (0.69)	56.8	37.8	5.3
… can be aggressive	-		3.65 (0.62)	68.2	34.2	2.6
… are looking physically different	-		3.27 (0.76)	37.3	50.8	11.8

Note. Remaining items lacked any factor loading higher than .40. The *h* (communality) refers to the sum of the squared factor loadings of that variable. Glb = greatest lower bound, Avg_iic = average inter-item-correlation.

Multivariate Analysis of Covariance: Familiarity and stereotypes

Non-significant Levene's tests for all four stereotype factors support the tenability of the assumption of homogeneity of variances; significance levels were p = .190, .105, .476, and .334, respectively. There was a statistically significant multivariate effect of familiarity on the four stereotype factors, which was corrected for the effects of gender, age, and education level (Λ = .970, F (8, 1754) = 3.328, p = .001). Significant but small between-subjects effects of familiarity were found for Friendly (F (2, 880) = 3.110, p = .045, $\eta 2$ =

.007), In need of help (F (2, 880) = 3.058, p = .048, $\eta 2$ = .007), and Give Nuisance (F (2, 880) = 9.118, p < .001, $\eta 2$ = .020). Further exploration of these between-subjects effects with pairwise post-hoc Bonferroni comparisons revealed no significant differences among the three familiarity levels on mean Friendly scores. For the In need of Help factor, the low-familiarity group demonstrated significantly lower mean scores than the high-familiarity group (M_{dif} = –0.10, SE = .042, p = .042). Concerning mean Give Nuisance scores, the low-familiarity group scored higher compared to both the average (M_{dif} = 0.17, SE = .041, p < .001) and the high-familiarity group (M_{dif} = 0.13, SE = .043, p = .006).

Hierarchical linear regression: Relationship with discrimination

Two linear regressions were performed to determine if the strength of the stereotypes predicted levels of social distance (M = 2.62; SD = 0.74) and helping behaviour (M = 3.66; SD = 0.61). Demographic variables predicted 0.2% of the variance in social distance and 1.8% of the variance in withholding help (see Table 2). Only the age of participants seemed to be predictive for withholding help, suggesting that an older age was related to more intention toward helping behaviour. After controlling for gender, age, and education level, adding familiarity to the model improved prediction of the variance with 2.6% and 2.7%, respectively, with more familiarity being related to less preferred social distance and more intention to helping behaviour. The stereotype factors predicted an additional 19.7% and 18.5% of the variance.

TABLE 2 | Predicting social distance and intention towards helping behaviour.

Predictor variables	Social distance				Helping behaviour			
	B (SE)	β	*P*	ΔR^2	*B (SE)*	β	*p*	ΔR^2
Step 1 – controls				.002				.018
Constant	2.798 (.131)		.000		3.516(.108)		<.001	
Gender	-.037 (.050)	-.025	.453		-.050(.041)	-.041	.227	
Age	-.017 (.015)	-.039	.244		.045(.012)	**.123**	<.001	
Education level	-.010 (.017)	-.020	.558		.001(.014)	.002	.958	
Step 2 –familiarity				.026				.027
Constant	3.060 (.140)		<.001		3.295 (.115)		<.001	
Gender	-.025 (.049)	-.017	.606		-.060(.040)	-.049	.141	
Age	-.017 (.015)	-.040	.234		.045(.012)	**.124**	<.001	
Education level	-.003 (.016)	-.006	.848		-.005(.014)	-.012	.721	
Familiarity	-.151 (.031)	**-.162**	<.001		.128(.026)	**.165**	<.001	
Step 3 –stereotype factors				.203				.192
Constant	2.723 (.324)		<.001		2.973 (.268)		<.001	
Gender	-.016 (.044)	-.011	.717		-.064 (.036)	-.053	.077	
Age	-.013 (.013)	-.031	.309		.039 (.011)	**.109**	<.001	
Education level	-.026 (.015)	-.053	.081		.010 (.012)	.025	.410	
Familiarity	-.115 (.028)	**-.123**	<.001		.094(.023)	**.122**	<.001	
Mean friendly	-.349 (.051)	**-.231**	<.001		.333(.042)	**.266**	<.001	
Mean in need of help	-.005 (.047)	-.003	.924		.047(.039)	.038	.228	
Mean nuisance	.339 (.045)	**.253**	<.001		-.255(.037)	**-.229**	<.001	
Mean unintelligent	.212 (.041)	**.164**	<.001		-.108(.034)	**-.101**	.001	

Note. Significant regression coefficients are marked in boldface type.

The stereotype factors Friendly, Give Nuisance, and Unintelligent emerged as predictors of both social distance and helping behaviour. A higher mean score on the Friendly factor was related to less preferred social distance and a higher intention to helping behaviour. In contrast, a higher mean score on both the Give Nuisance and Unintelligent factors was related to more preferred social distance and less intention toward helping behaviour.

Qualitative approach: Complementary stereotypes and salience of stereotypes

To categorise the data from the open-ended question a qualitative approach was used with both selective-deductive and open-inductive elements. There were missing data for 25 participants (2.80%) on the open-ended question. Data from the 867 remaining participants, which was divided into 1227 quotations, varied from a few words (e.g., 'Down syndrome, different behaviour, innocence') to longer phrases or even several sentences (e.g., "I think of people who can be just as happy or unhappy as other people and who generally behave socially and like to do things. They are freer in their behaviour and they know less shyness").

Concerning complementary stereotypes, the quotations that were not similar to items in one of the four factors (n = 565) were open coded. A threshold of 10 quotations per stereotype was held; the stereotypes that upheld this threshold are presented in Table 3. Thereby, 66 quotations were not categorised; for example, only four quotations indicated that people with intellectual disabilities are musically gifted, and this stereotype thus did not uphold the threshold of 10 quotations. Complementary stereotypes mainly referred to areas of dependence (e.g., less independent) and incompetence (e.g., low levels of social skills, impairments in thinking).

With respect to the salience of the stereotypes, the frequency with which stereotypes were reported was investigated. Table 4 shows the frequency of quotations that belong to items under one of the four factors (n = 647 quotations). Because the number of items differed per factor, the proportional frequency with which the stereotypes were reported was calculated. Looking into this proportional frequency, the 'in need of help' stereotypes were most frequently reported, followed by the stereotypes 'friendly' and 'unintelligent'. The stereotypes regarding 'nuisance' were infrequently reported, and thus seem to be less salient. Moreover, when looking into the frequency with which the complementary stereotypes were reported, 'being less independent' was the most frequently reported stereotype, with half the quotations, followed by 'low levels of social skills' and 'impairments in thinking'.

TABLE 3 | Complementary stereotypes based on quotations and codes analysed from the open question.

Stereotypical category	Illustrations / subcategories	Example quotations	# quotations
Less independent	Less independent	"*not the capacity to develop as an independent individual*"	166
	More reliant on others	"*more reliant on others for support and attention*"	
	Specific examples or areas of (in) dependence Having difficulties in making decisions and taking responsibilities.	"*some can work and take care of themselves, others are dependent*"	
Low levels of social skills	Socially smart people (*n* = 6 quotations)	*"social people, perfectly fine to have contact with"*	81
	Lacking social skills	"*less socially skilled"*	
	Having difficulties with communication	*"difficulty in making contact with other people"*	
	living in their own world	*"people who very much live within themselves"*	
Impairments in thinking	A child's way of thinking	*"most of them have the mind of a child and not of an adult*"	64
	Specific impairments in thinking	*"they forget that you asked them something*"	
Visibility	A visible impairment or a reference to specific visible symptoms (*n* = 43 quotations)	*"Spasms" "wheelchair*"	51
	Some specifically mentioned Down syndrome as a visible intellectual disabilities.	"*from the outside you do see nothing sometimes*"	
	Not visible (*n* = 8 quotations)		
Naïve/open		*"pure" "spontaneous"*	*39*
Can be aggressive		*"I know that people with intellectual disabilities can also be aggressive*"	37
Slow		*"slow", "they need more time to do something"*	37
Disinhibited		*"people without inhibitions like normal people" "impulsive*"	24
Not categorised	(*n* = 66 stereotype codes) were mentioned infrequently (< 10 times) and therefore not categorised.	E.g., "*humorous"* (*n* = 6), "*musically gifted"* (*n* = 4), "*in need of attention"* (*n* = 10).	<10

TABLE 4 | Frequency of quotations in the free response question referring to stereotype-items used in the trait rating scale.

Factor [a]	# Literal	Example literal	# Synonym	Example synonym	Total frequency	Proportional frequency [b]
Friendly (5 items)	110	*'friendly persons'*	173	*'agreeable in contact'*	283	52
In need of help (3 items)	32	*'they need help'*	179	*'in need of care'*	211	70
Nuisance (5 items)	18	*'Nuisance to the neighbourhood'*	33	*'someone who stays a child'*	51	10
Unintelligent (2 items)	18	*'very low IQ'*	84	*'people who are behind in their mind'*	102	51

Note. [a] The factors refer to the all the items under this factor. [b] Proportional frequency refers to the number of quotations divided by the number of items under the factor.

DISCUSSION

This study examined a prominent cognitive component of stigmatisation of people with intellectual disabilities, namely the appearance and salience of stereotypes of people with intellectual disabilities within a population sample of the Dutch general public (n = 892). Also, the relationships of these stereotypes with (1) levels of familiarity with intellectual disabilities, and (2) discrimination were explored. First, four main stereotype-factors were found: 'friendly', 'in need of help', 'unintelligent', and 'a nuisance'. The factors 'friendly', 'in need of help', and 'unintelligent' were demonstrated to be salient stereotypes due to their above average scores (trait rating scale) and frequent report in the open-ended question. Of these three, 'in need of help', was the most frequently reported. In accordance, expressed stereotypes complementary to the trait-rating scale mainly referred to areas of dependence and incompetence; being 'less independent' was the most frequently reported complementary stereotype. Contrarily, 'nuisance' was not found to be a salient stereotype for people with intellectual disabilities within the present study context. Stereotype-items in the 'nuisance' factor (e.g., 'are criminal', 'are a nuisance') received low average scores and were infrequently reported in the open-ended question. Second, concerning the relationship of stereotypes with familiarity, participants who were unfamiliar with people with intellectual disabilities considered them to be less 'in need of help' and more of 'a nuisance' compared to participants who were familiar with people with intellectual disabilities. Third, low levels of discriminatory intentions were reported by participants (i.e., low levels of social distance and a high intention to show helping behaviour); whereby a stronger 'friendly' stereotype predicted lower levels of discrimination, while, contrarily, a stronger 'nuisance' or 'unintelligent' stereotype predicted higher levels of discrimination.

Clearly, people with intellectual disabilities seem to experience a different form of stigmatisation than people with mental illness, a field upon which researchers of

intellectual disabilities stigma have based many of their concepts (Ditchman et al., 2013). Nuisance stereotypes are commonly assigned to people with mental illness or substance use disorders (van Boekel et al., 2015; van 't Veer et al., 2006), though, as the present findings illustrate, not to people with intellectual disabilities. Similarly, the 'friendliness' stereotype that was found to be salient for people with intellectual disabilities, is hardly assigned to people with substance use disorders or other mental illnesses. Notably however, there is frequent comorbidity of intellectual disabilities and criminal offending, substance use, and psychopathology (Matson & Shoemaker, 2011) and therefore also a frequent use of psychiatric services by people with intellectual disabilities. It is questionable whether the general public is aware of this frequent comorbidity. Moreover, future research may examine which stigma experiences are stronger for people with intellectual disabilities and psychiatric comorbidity (i.e., the psychiatric or intellectual disabilities stigma). Also, both in anti-stigma campaigns as well as in rehabilitation programmes there seems to be the need to pay specific attention to the unique stigma of people with intellectual disabilities.

It should be noted that some stereotypes (i.e., unintelligent, in need of help), seem to relate to the criteria that are often used to diagnose intellectual disabilities (i.e., deficits in intellectual functioning, deficits in adaptive functioning) (American Psychiatric Association, 2013). There is a complex and intricate relationship between diagnostic labels and public stereotypes (Ben-Zeev, Young, & Corrigan, 2010; Corrigan, 2006; Scior et al., 2013). One of the risks of stereotypes, irrespective of their congruity with diagnostic criteria, is that members of stereotyped out-groups are seen in a more homogeneous way than in-groups (Ben-Zeev et al., 2010). For example, the range of Intelligence Quotients in people with intellectual disabilities (<20 - 70) is equally wide as the range of Intelligence Quotients in the average population (70-130). Concerning people with intellectual disabilities, the stereotype 'unintelligent' can convey the hazard that they might be seen as homogeneously unintelligent which potentially relates to pessimistic views about peoples capabilities. Therefore, the main point of these stereotypes is that they partly define inter-personal contact. The challenge is to interpret the other (with or without intellectual disabilities) with respect for his/her authenticity (Meininger, 2001).

A subtle effect of stereotyping on people's ability to realise valued life and rehabilitation goals such as employment, independent housing, or a valuable and strong social network may be expected. The demonstrated main stereotypes of intellectual disabilities comprise both positive (i.e., 'friendly') and negative (e.g., 'unintelligent', 'less independent') traits which were related to levels of discrimination; but these levels were generally low (i.e., low levels preferred social distance and withholding help). The low levels of explicit discrimination are in accordance with previous studies (Ouellette-Kuntz, Burge, Brown, & Arsenault, 2010; Scior et al., 2013; Werner, 2015). However, the ambivalence of stereotypes may lead to more subtle forms of discrimination (e.g., Werner, 2015). For example, due to stereotypes of being not independent, in need of help, and friendly, people with

intellectual disabilities may be tolerated in the community but, not be taken seriously, not receiving possibilities for self-determination, or not having the opportunity to make their own choices (Bekkema et al., 2015; Ditchman, Kosyluk, Lee, & Jones, 2016; Kjellberg, 2002). Moreover, the stereotypes referring to incompetence of people with intellectual disabilities might justify the denial of many opportunities to participate in mainstream society (Biernat & Dovidio, 2000). Existing measures with respect to benevolence (i.e., people are childlike and need to be cared for) or authoritarianism (i.e., people are irresponsible, so life decisions should be made by others) may partially capture these experiences and therefore might reveal more stigmatisation than do measures of social distance (Brockington, Hall, Levings, & Murphy, 2000; Corrigan et al., 2005; Jahoda et al., 2010). Moreover, one of the key foci of professionals, when keeping in mind the stereotypes of intellectual disabilities, might be to enhance and support guided decision-making regarding valued life goals as to enable people to experience agency within their own life (Douglas & Bigby, 2018).

A second potential effect of ambivalent stereotyping that may inform anti-stigma interventions concerns the opportunities of people with intellectual disabilities to advocate for their own rights. When addressing groups with ambivalent stereotypes, people have the tendency to address only positive stereotypes and omit negative stereotypes (i.e., stereotyping by omission; (Bergsieker, Leslie, Constantine, & Fiske, 2012). Addressing only positive stereotypes may increase the perceived harmony between groups (i.e., "We are having fun together", "Everything is fair and 'cosy'") while making it more difficult to address intergroup inequalities (Saguy, Tausch, Dovidio, & Pratto, 2009). People with intellectual disabilities seem to experience difficulties asserting their rights (Beart, Hardy, & Buchan, 2005). For example, people with intellectual disabilities continue to be of low priority in government policy and programmes, and they often are not well represented in the disability rights movement (Scior et al., 2016). Ambivalent stereotypes may undergird this situation, making it especially challenging for people with intellectual disabilities and their advocates to evaluate inequalities critically. Therefore, protest components may make a valuable contribution to anti-stigma interventions where intergroup contact is proposed as a main strategy, with promising results for tackling stigmatisation towards people with intellectual disabilities (Corrigan & Watson, 2002; Seewooruttun & Scior, 2014). Protest, which refers to the education of the general public about inequalities experienced by people with intellectual disabilities, has been demonstrated to generate stronger emotional reactions and improvement in the support of empowerment and discouragement of sheltering than an intervention that focused on the similarity between people with and without intellectual disabilities (Walker & Scior, 2013).

Although this study has considerable strengths, there are also limitations that need to be addressed. The stereotype items of the stereotype trait-rating scale may have influenced the answers on the open-ended question (i.e., priming), as the open-ended question was asked at the end of the questionnaire. However, the prior items may also have

made participants' beliefs more accessible (Tourangeau & Rasinski, 1988). In addition, the open-ended question provided information about the salience of stereotypes and input to determine if the Likert-type scale should be complemented with stereotypes in future research. Moreover, this study has not included a social desirability measure. Yet, in a review, social desirability has been shown to be only weakly correlated, if at all, with stigma, as measured on direct scales in studies into public stigma of intellectual disabilities (Scior, 2011). Also in this individual anonymous internet survey with the possibility of backtracking, we would expect no large effects of social desirable answering (Richman, Weisband, Kiesler, & Drasgow, 1999).

People with intellectual disabilities are judged by the general public with an ambivalent set of stereotypes. These ambivalent stereotypes may lead to the experience of subtle forms of stigma, such as not being taken seriously and not being granted rights, which can induce inequality and limited opportunities for participation. Continuing exploration of experiences of stigmatisation by people with intellectual disabilities is needed in an effort to discover social factors that inhibit their freedom to act on what they perceive as valuable. This may provide input for the development and sophistication of anti-stigma interventions and thereby potentially contribute to rehabilitation programs and participation opportunities for people with intellectual disabilities.

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Chapter 3

Familiarity with people with intellectual disabilities, stigma, and the mediating role of emotions among the Dutch general public

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ABSTRACT

Background

Stigma can hamper full inclusion of people with intellectual disabilities in society. For other minority groups, higher levels of familiarity with these groups have been shown to relate to lower levels of stigma, whereby emotions can play a mediating role. However, concerning people with intellectual disabilities, there is limited knowledge regarding the general public's levels of familiarity, its relationship with stigma, and the role of emotions in this relationship.

Method

A cross-sectional survey was conducted among a nationally representative sample of the Dutch population (*n* = 892). The relationship between levels of familiarity and different measures of stigma representing cognitive, emotional, and behavioural aspects of stigma (i.e., attributions, emotions, discrimination) was examined. Emotions (fear, anger, and sympathy) were studied as a mediator in the relationship between familiarity and discrimination (i.e., social distance, and intention to help).

Results

Participants who reported no familiarity in real life with people with intellectual disabilities (30.6% of the population sample) demonstrated higher levels of stigma (attributions, emotions, discrimination) than participants who reported any form of real-life familiarity (69.4% of the sample). Fear was found to be the most important mediator of the relationship between familiarity and discrimination.

Discussion

The findings stress the continuing importance to advocate for people with intellectual disabilities to be recognised and become known within society. This increased familiarity might reduce stigma and increase positive experiences of inclusion. Support workers may have a vital role in this process. The importance of fear in the relationship between familiarity and discrimination may inform future research and anti-stigma interventions.

Following four decades of deinstitutionalization policies, the daily lives of people with intellectual disabilities have been relocated from institutions outside urban areas into the community (Johnson & Traustadottir, 2005). This initial physical integration has increased the visibility of people with intellectual disabilities as a minority group. Yet meanwhile, it has also made more apparent, the challenge of going beyond physical inclusion to true participation and inclusion of people with intellectual disabilities (e.g., Cooney et al., 2006; Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014). Stigmatisation can be a pressing impediment for inclusion and participation (Scior et al., 2016).

Stigmatisation refers to the situation in which a person deviates from social norms and is thereby negatively evaluated by others, and reduced "from a whole and usual person to a tainted, discounted one" (Dovidio, Major, & Crocker, 2000; Goffman, 1963, p3). One factor that has consistently been shown to challenge and decrease stigmatisation concerns people's familiarity with a minority group (Clement et al., 2012; Corrigan, Green, Lundin, Kubiak, & Penn, 2001; Pettigrew & Tropp, 2006). Although, as a minority group, people with intellectual disabilities are more visible within society nowadays, knowledge as to whether this co-occurs with high levels of familiarity and whether this familiarity relates to less stigmatisation is still limited.

Within the Netherlands roughly 0.9% of the population has received support from the public intellectual disability care system in 2011 (Ras, Verbeek-Oudijk, & Eggink, 2013). In Western classifications, intellectual disabilities refer to limitations in both cognitive and adaptive functioning, being present before adulthood (before age 18; American Psychiatric Association, 2013; World Health Organization, 2001). Concerning the support system for people with intellectual disabilities within the Netherlands, complex care (24-hr support) is provided through centralised institutions and covered by the Long-Term Care Act (in Dutch: Wet Langdurige Zorg), whereas less intensive care and support is provided within home settings, falls under the responsibility of local authorities, and is covered by the Social Support Act (in Dutch: Wet Maatschappelijke Ondersteuning). The goal of a more inclusive society is one of the fundamental ideas behind Dutch policy reforms (e.g., UN convention ratification, and the Participation Law), yet realization of this goal is still beyond reach (Woittiez, Eggink, Putman, & Ras, 2018).

PERSONAL CONTACT, FAMILIARITY, AND STIGMA OF PEOPLE WITH INTELLECTUAL DISABILITIES

Stigma and prejudice studies in various minority groups have clearly demonstrated that personal contact with a group reduces negative attitudes (i.e., intergroup contact theory; Pettigrew & Tropp, 2006). Yet, adhering to specific conditions for contact (i.e., equal status, common goals, intergroup cooperation, and support of authorities) may enhance these effects even further (Allport, 1954; Pettigrew & Tropp, 2006). Likewise, having contact with people with intellectual disabilities also seems to have the potential to decrease

stigmatisation (e.g., preferred social distance) (Blundell, 2014; Scior, 2011; Seewooruttun & Scior, 2014; Walker & Scior, 2013). These studies in the field of intellectual disabilities that examined the relationship between contact and stigma have assessed previous contact mostly as a dichotomous question (yes/no). In such questions, participants are asked whether they have had previous personal contact with people with intellectual disabilities or not (Blundell, Das, Potts, & Scior, 2016).

In addition to these studies that have assessed the effect of reporting previous personal contact on levels of stigmatisation, a number of related studies have focused on people's current extent of familiarity with a minority group and associated levels of stigmatisation. The concept of familiarity does not refer to whether or not people have had contact with a minority group but refers instead to varying degrees of intimacy or closeness that people can have with a minority group. These levels can range from no familiarity at all, to for example working with people from a minority group or personally belonging to a minority group (Corrigan et al., 2001). One study in the field of intellectual disabilities studied varying degrees of intimacy and its relationship to attitudes towards sexuality. This study demonstrated that higher levels of familiarity were related to more positive attitudes toward people with intellectual disabilities' ability to parent and rear children when provided with the right support (Ditchman, Easton, Batchos, Rafajko, & Shah, 2017).

So far, however, studies in the field of intellectual disabilities have mainly focused on the dichotomy of reporting prior contact (yes/no) to predict stigma (Horner-Johnson et al., 2002; Scior, Potts, & Furnham, 2013; Werner, 2015; Yazbeck, McVilly, & Parmenter, 2004). This previous contact was consistently related to more positive attitudes, for example toward inclusion (Scior, 2011). Yet, Blundell and colleagues (2016), in a study aiming to specifically examine the role of contact in relation to lay responses to intellectual disabilities, demonstrated that a more nuanced variable (i.e., including frequency, closeness and nature of the relationship) seems to be more predictive of stigma than a dichotomous contact variable. More specifically, they found reported closeness of a relationship as the only individually predictive variable of discrimination (Blundell et al., 2016). Also Morin, Rivard, Crocker, Boursier, and Caron (2013) demonstrated that the perceived quality of the relationship with people with intellectual disabilities demonstrated the largest effect size concerning levels of interaction (i.e., closely related to social distance and intention to help) when compared with the frequency of contact and the number of persons with intellectual disabilities participants reported to know (Morin et al., 2013).

To date and to our knowledge, no studies in the field of intellectual disabilities have used high-quality population samples to describe familiarity, referring to the degree of intimacy/closeness of the contact, stigma, and the relationship between stigma and familiarity (e.g., Blundell et al., 2016; Ouellette-Kuntz, Burge, Brown, & Arsenault, 2010).

EMOTIONS AS MEDIATOR OF THE RELATIONSHIP BETWEEN FAMILIARITY AND DISCRIMINATION

Stigmatisation includes negative cognitions, negative emotional reactions, and discriminatory behaviour (Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003; Dovidio et al., 2000). Especially, emotional reactions have been demonstrated to be foundational in the stigmatisation of minority groups. For example, emotions seem to predict discrimination more strongly than cognitions (Cuddy, Fiske, & Glick, 2007). Emotions may elucidate why being less familiar with a minority group may relate to higher levels of stigma (Angermeyer, Holzinger, & Matschinger, 2010; Pettigrew & Tropp, 2006). Specifically, Pettigrew and Tropp (2006) suggest that intergroup anxiety might mediate the relationship between familiarity and prejudice. That is, less familiarity with a group may induce fear toward that group, which predicts higher levels of discrimination. Regarding mental illness, the relationship between familiarity and social distance was to a considerable extent mediated by emotional reactions (e.g., positive emotions, anger, or fear) (e.g., Angermeyer et al., 2010). Also, concerning people with dementia, fearful reactions were especially found to negatively affect beliefs and attitudes about dementia (von dem Knesebeck, Angermeyer, Lüdecke, & Kofahl, 2014). Emotions toward people with intellectual disabilities have been found to predict levels of social distance and withdrawal behaviour (Scior, Connolly, & Williams, 2013; Werner, 2015; Wilson & Scior, 2015). Yet, to date, no studies in the field of intellectual disabilities have examined whether specific emotions may mediate the relationship between familiarity and discrimination.

THIS STUDY

For people with intellectual disabilities, the challenge of gaining full inclusion can be impeded by stigma. Because of its potential effect in decreasing stigma, it is essential to examine the general public's familiarity with people with intellectual disabilities. A central tenet of this study was to obtain a high-quality representative sample of the Dutch population to enable an account of familiarity and stigma and its relationship on a population level. To consider the cognitive, emotional and behavioural aspects of stigma, measures included *attributions* (cognitions), *emotions*, and *discrimination* (behaviour). In this study, three research aims were followed: (a) to examine the present level of the Dutch general public's familiarity with people with intellectual disabilities, as well as the general public's self-reported levels of stigma; (b) to study the relationship between familiarity on the one hand and attributions, emotions and discrimination on the other hand; (c) to explore the mediating role of emotions in the relationship between familiarity and discrimination (see, Figure 1). Our main hypothesis was that low levels of familiarity would relate to higher levels of stigma and that emotions would play a mediating role in this relationship. More specifically, low levels of familiarity would relate to: (a) higher levels of perceived dangerousness and perceived personal responsibility (i.e., attributions); (b)

higher levels of fear and anger, and lower levels of sympathy; and (c) higher levels of social distance and lower levels of willingness to help (i.e., discrimination). Moreover, concerning the mediating effect of emotions, we hypothesised that (a) anger and fear would play a mediating role in exacerbating levels of discrimination in case of low familiarity, and that (b) sympathy in mediating the relationship between familiarity and discrimination would have a positive effect.

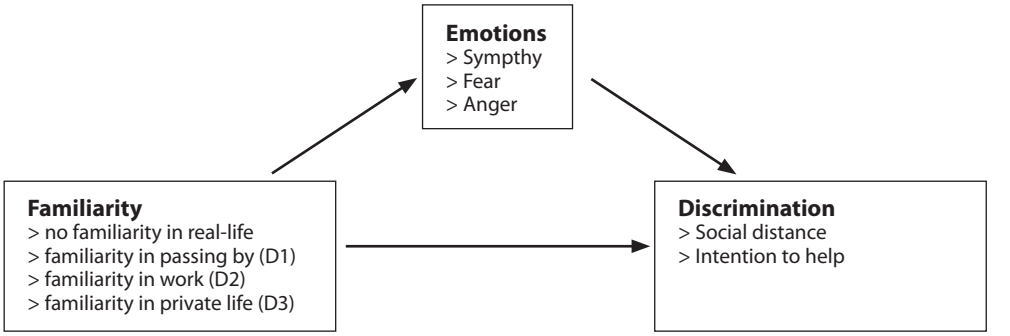

FIGURE 1 | Mediation-model that is tested for the three emotions and two behavioural intention measures (see also addendum).

METHOD

Participants

A cross-sectional survey was conducted among a large nationally representative sample of the Dutch population using the Longitudinal Internet Studies for the Social Sciences (LISS) panel in February 2015 (www.lissdata.nl). CentERdata (Tilburg University, The Netherlands), a research institute specialised in quantitative data collection, governs the panel as well as the data collection. CentERdata abides by the European General Data Protection Regulation (GDPR). For the LISS panel, a true probability sample of households was drawn from the population register in cooperation with Statistics Netherlands. Participants consented to become panel members for monthly internet surveys. For each completed questionnaire, participants receive a monetary reward. The LISS panel consists of 5,600 households with 8,735 panel members 16 years of age and older. Households that could otherwise not participate were equipped with a computer with an internet connection. No self-selection into the sample was possible. The main aim of the panel is to provide researchers with a high-quality representative population sample for scientific and policy research. Representativeness is continuously maintained.

For this study, we used a random selection of 1,093 panel members. Response rate (81.6 %) and outcome data (95.5% did complete the questionnaire) were high. The sample thus consisted of 892 members of the Dutch general public. Demographics of the study sample were highly similar to demographics of the Dutch population according to Statistics Netherlands 2015.

Measures

For all measures, a bilingual speaker of Dutch and English was involved in translating items from English to Dutch to ensure a similar meaning across languages. To consider the cognitive, emotional and behavioural aspects of stigma, measures included *attributions* (cognitions), *emotions*, and *social distance and intention to help* as intentions towards discrimination (behaviour). The questions were introduced with the following phrases: "*The survey you are filling out concerns people with intellectual disabilities. You can also answer the questions if you have little or no experience with people with intellectual disabilities. This survey addresses your opinion and is not about right or wrong answers.*"

Familiarity

Familiarity refers to varying degrees of intimacy or closeness that people can have with a minority group (Corrigan et al., 2001). Familiarity was assessed by the Level of Contact Report which was found to be a valid and reliable measure of familiarity with people with mental illness (Corrigan et al., 2001; Holmes, Corrigan, Williams, Canar, & Kubiak, 1999). Within this study, the word 'mental illness' in the survey items was replaced with the word 'intellectual disabilities'. A 12-item list with situations of varying exposure to people with intellectual disabilities was presented. Participants were asked to indicate all of the situations that were applicable to them. For example, *"I have watched a documentary on the television about intellectual disabilities"*, or *"My job includes providing services to persons with an intellectual disability"*. The familiarity-index was the rank score of the most intimate situation that was checked by the participant. Because of its ranking nature, the familiarity scale originally concerns an ordinal variable (i.e., a rank score) and not an interval variable (i.e., continuous). Although some previous studies have used the scale as a continuous variable (Ditchman et al., 2017; Holmes et al., 1999), there have been no studies that provide evidence that the ranking of this particular scale has values with equal intervals. For this reason, to avoid any risk, we have interpreted this scale as ordinal data. The data was merged from twelve categories into four groups of familiarity to enable analyses. , These four groups were: 1) 'no familiarity in real-life' (rank-item 1–4; e.g., watching a documentary), 2) 'familiarity in passing by' (rank-item 5; i.e., observing people on a frequent basis), 3) 'familiarity in work' (rank-item 6–8; e.g., providing services), and 4) 'familiarity in private life' (rank-item 9–12; e.g., friend of the family) (see also, Table 1).

Attributions

As a cognitive measure of stigma, two types of attributions were assessed that have been demonstrated to be robustly related to mental illness stigma: 'perceived responsibility' and 'perceived dangerousness' (Corrigan et al., 2002). We replicated the items concerning perceived responsibility (2 items) from Corrigan and colleagues (2003) (e.g., "*A person with an intellectual disability is him/herself responsible for that disability.")*. The items concerning perceived dangerousness (3 items) were replicated from Corrigan and colleagues (2002) (e.g., "*A person with an intellectual disability is dangerous.")*. Both these measures have

proven predictive validity within the field of mental illness. For all 5 items, participants had to indicate to what degree they would agree with the statements, using a scale ranging from 1 = *totally disagree* to 5 = *totally agree*. The internal reliability was satisfactory for the personal responsibility scale (Cronbach's α = .72) and good for the dangerousness (Cronbach's α = .80) scale.

Emotions

In previous research, three types of emotions (i.e., fear, anger, and pity) have consistently been distinguished as separate emotional reactions towards people with mental and cognitive disorders (e.g., Angermeyer & Matschinger, 2003). We assessed these emotions using nine items replicated from Von dem Knesebeck and colleagues (2014). Similar to previous studies, the item *"I have pity"*, was removed from further analyses as it loaded highly on all three emotions and therefore was not specific. The 'pity' scale was renamed 'sympathy' as it measures positive sympathetic feelings instead of the more negatively connoted 'pity' (Scior, Connoly, et al., 2013). Items were introduced with the question: *"How would you react to a person with intellectual disabilities? Please indicate how you would evaluate the emotional reactions mentioned."* The items were coded from 1 = *not at all correct* to 5 = *completely correct,* indicating that a higher score connotes the increased presence of a given emotion. Cronbach's alphas were respectively .62 for sympathy ("*I feel sympathy", "I feel the need to help this person"),* .79 for fear (*"I feel insecure", "I feel fear", "I feel uncomfortable"*), and .69 for anger *("I react angrily", I feel annoyed", "I experience incomprehension").*

Discrimination – Social distance

Social distance refers to people's inclination to avoid contact with individuals with specific conditions (Whatley, 1959) and thereby assesses people's behavioural intention towards discrimination. To assess social distance, items were replicated from a study of Link, Phelan, Bresnahan, Stueve, and Pescosolido (1999). Participants were asked how they would rate their willingness in the following interactions with a person with intellectual disabilities: 1) *"to move next door to the person"*, 2) *"spend an evening socializing with the person"*, 3) *"make friends with the person"*, 4) *"start working closely with the person",* and 5) "*have the person marry into the family"*. A five point Likert-scale was used, ranging from 1 = *definitely not* to 5 = *definitely*. The internal reliability of this scale was good (Cronbach's α = .84). Recoding of the scale resulted in a higher score indicating a greater desire for social distance.

Discrimination–Intention towards helping behaviour

The intention towards helping behaviour refers to the tendency to provide help or to avoid helping people with certain conditions (Corrigan et al., 2003). For this measure, statements were replicated from Corrigan and colleagues (2003). We asked participants to what degree they would agree with a set of statements (1 = *totally disagree* to 5 = *totally agree*). The statements were: (1) *"If I were an employer, I would interview someone*

with an intellectual disability for a job", (2) *"I would share a car pool with someone with an intellectual disability each day"*, (3) *"If I were a landlord, I probably would rent an apartment to someone with and intellectual disability"*, and (4) *"I am certain I would help someone with an intellectual disability"*. A satisfactory internal reliability of the scale was found (Cronbach's α = .79). Because a higher score connotes a higher intention towards helping behaviour, a lower score on this scale is indicative of a more discriminatory intention.

Analyses

We conducted three types of analyses. First, descriptive statistics were presented regarding familiarity and stigma measures. Second, to examine the difference between the four familiarity categories on stigma measures, multivariate analyses (i.e., multiple ANOVA's) were conducted for the different stigma measures. To reduce multiple testing and changes on Type I-error, Helmert contrasts were used as a post-hoc test whereby each level of familiarity is compared to the mean of the subsequent levels. Third and finally, a mediation analysis was conducted to examine whether emotions of participants (i.e., fear, anger, sympathy) may mediate the relationship between familiarity (i.e., four categories) and discrimination (i.e., social distance and intention to help). The analyses were conducted following the strategy of Hayes and Preacher (2014) using structural equation modelling (Hayes & Preacher, 2014) (see online supplemental material for the code for data analysis) in the program Mplus version 8. The significance of indirect effects was evaluated using a bootstrapping procedure. This involved drawing 1,000 bootstrapped samples from the data in order to estimate the indirect effect for each of the resampled data sets (Preacher & Hayes, 2004). As a result, a 95% confidence interval of the indirect effect was available to evaluate the results.

RESULTS

Descriptive Results

Participants

Participants were 892 members of the Dutch general population, 421 male, and 471 female participants with ages ranging from 16 to 90 years of age ($M = 49.32$, $SD = 17.81$). Reported levels of accomplished education were low education 25.7% (i.e., elementary school, or secondary school preparing for vocational education); middle education 38.1% (secondary school preparing for (applied) university, or vocational education); and high education 33.7% (i.e., (applied) university degree) (2.5% other). Participants reported in 90.5% of the cases a Caucasian background, in 6% of the cases a non-Caucasian background, for 3.5% of the sample, this data was missing.

Levels of familiarity

Table 1 demonstrates the descriptive statistics of the general public's familiarity with people with intellectual disabilities. Based on these data, a third of the general public can be considered as having no familiarity in real life, because their most intimate contact with people with intellectual disabilities existed in 'passing by' or by 'watching television' (i.e., category 1). Yet, two thirds of the population reported some form of familiarity with people with intellectual disabilities (i.e., categories 2-4).

TABLE 1 | *Frequency Statistics of Levels of Familiarity Assessed Within the Dutch General Public (n* = 892).

Familiarity items by category		***f***	**%**
1.	**No familiarity in real-life**	**273**	**30.6**
	I have never observed a person that I was aware had an intellectual disability.	14	1.6
	I have observed, in passing, a person I believe may have had an intellectual disability.	61	6.8
	I have watched a movie or television show in which a character depicted a person with an intellectual disability.	90	10.1
	I have watched a documentary on the television about intellectual disabilities.	108	12.1
2.	**Familiarity in passing by**	**240**	**26.9**
	I have observed persons with an intellectual disability on a frequent basis	240	26.9
3.	**Familiarity in work context**	**98**	**11.0**
	My job involves providing services/treatment for persons with an intellectual disability.	30	3.4
	My job includes providing services to persons with an intellectual disability.	24	2.7
	I have worked with a person who had an intellectual disability at my place of employment.	44	4.9
4.	**Familiarity in private life**	**281**	**31.5**
	A friend of the family has an intellectual disability.	71	8.0
	I have a relative who has an intellectual disability.	197	22.1
	I live with a person who has an intellectual disability.	8	0.9
	I have an intellectual disability.	5	0.6
Total		*892*	100

Note. The frequency (*f*) of the rank order is the number of times that participants rate this answer as their highest form of familiarity. Categories based on the rank order scores were used for analysis.

Levels of stigma

Concerning the sample as a whole, Table 2 demonstrates low levels of attributed personal responsibility and dangerousness, low levels of emotions of anger and fear, and above average levels of sympathy. Moreover, the average social distance score is at the positive side of the scale (that is: people are likely to associate with people with intellectual disabilities). This is similar for the average level of intention to help (meaning: people agree that they would be willing to help).

TABLE 2 | *Descriptive and Correlation Statistics of Stigma Measures Assessed within the Dutch General Public (N = 892).*

	Attributions		**Emotions**			**Discrimination**	
	Responsibility	*Dangerousness*	*Anger*	*Fear*	*Sympathy*	*Social Distance*	*Intention to help*
Responsibility	1	.533**	.444**	.348**	-.161**	.177**	-.233**
Dangerousness		1	.518**	.624**	-.215**	.385**	-.450**
Anger			1	.625**	-.074*	.295**	-.307**
Fear				1	-.173**	.410**	-.403**
Sympathy					1	-.419**	.428**
Social Distance						1	-.651**
Intention to help							1
M	1.53	1.98	1.91	1.94	3.41	2.62	3.66
(SD)	(0.61)	(0.65)	(0.64)	(0.70)	(0.68)	(0.74)	(0.61)

Note. All scales are 5-point Likert scales with a higher scores indicating higher levels of the variable. **. Correlation is significant at the 0.01 level (2-tailed). *. Correlation is significant at the 0.05 level (2-tailed).

RELATIONSHIPS BETWEEN FAMILIARITY AND STIGMATISATION

Concerning the relationship between familiarity and measures of stigma, we found a significant multivariate effect of familiarity (i.e., four categories) on the three measures of stigmatisation (i.e., attributions, emotions, discrimination) ($\Lambda = .904$, $F(21, 2519) = 4.277$, $p < .001$, partial $\eta^2 = .03$). Moreover, for all specific stigma measures, significant group differences between the categories of familiarity were found: Attribution $_{responsibility}$ $F(3, 883) = 9.522$, $p < .001$, partial $\eta^2 = .03$; Attribution $_{dangerousness}$ $F(3, 883) = 10.056$, $p < .001$, partial $\eta^2 = .03$; Emotion $_{anger}$ $F(3, 883) = 5.898$, $p < .001$, partial $\eta^2 = .02$; Emotion $_{fear}$ $F(3, 883) = 15.374$, $p < .001$, partial $\eta^2 = .05$; Emotion $_{sympathy}$ $F(3, 883) = 4.423$, $p = .004$, partial $\eta^2 = .02$; Discrimination $_{social\ distance}$ $F(3, 883) = 9.779$, $p < .001$, partial $\eta^2 = .03$; Discrimination $_{intention\ to\ help}$ $F(3, 883) = 10.424$, $p < .001$, partial $\eta^2 = .03$.

The between-subject effects were further explored using post-hoc Helmert contrasts. In these contrasts, a fairly consistent finding appeared (see Table 3 and Figure 2). For all stigma measures, significant differences were found between participants in the category that reported 'no familiarity in real-life' (i.e., category 1) on the one hand and the remaining three categories of familiarity (i.e., '(2) familiarity in passing by', '(3) familiarity in work', and '(4) familiarity in private life') on the other hand. Thus, participants who reported 'no familiarity in real-life', attributed more responsibility and more dangerousness to people with intellectual disabilities; they reported higher levels of fear and anger; higher levels of preferred social distance, and lower intention towards helping behaviour than participants in the other three categories of familiarity. The effect was largest for the level of fear that people reported.

Concerning levels of discrimination (i.e., social distance and intention to help), not only did participants who reported 'no familiarity in real-life' demonstrate higher levels of stigma as compared to the other categories. However, participants in the category 'familiarity in passing by' also reported higher discrimination scores than participants in the subsequent categories of familiarity (i.e., 'familiarity in work' and 'familiarity in private life').

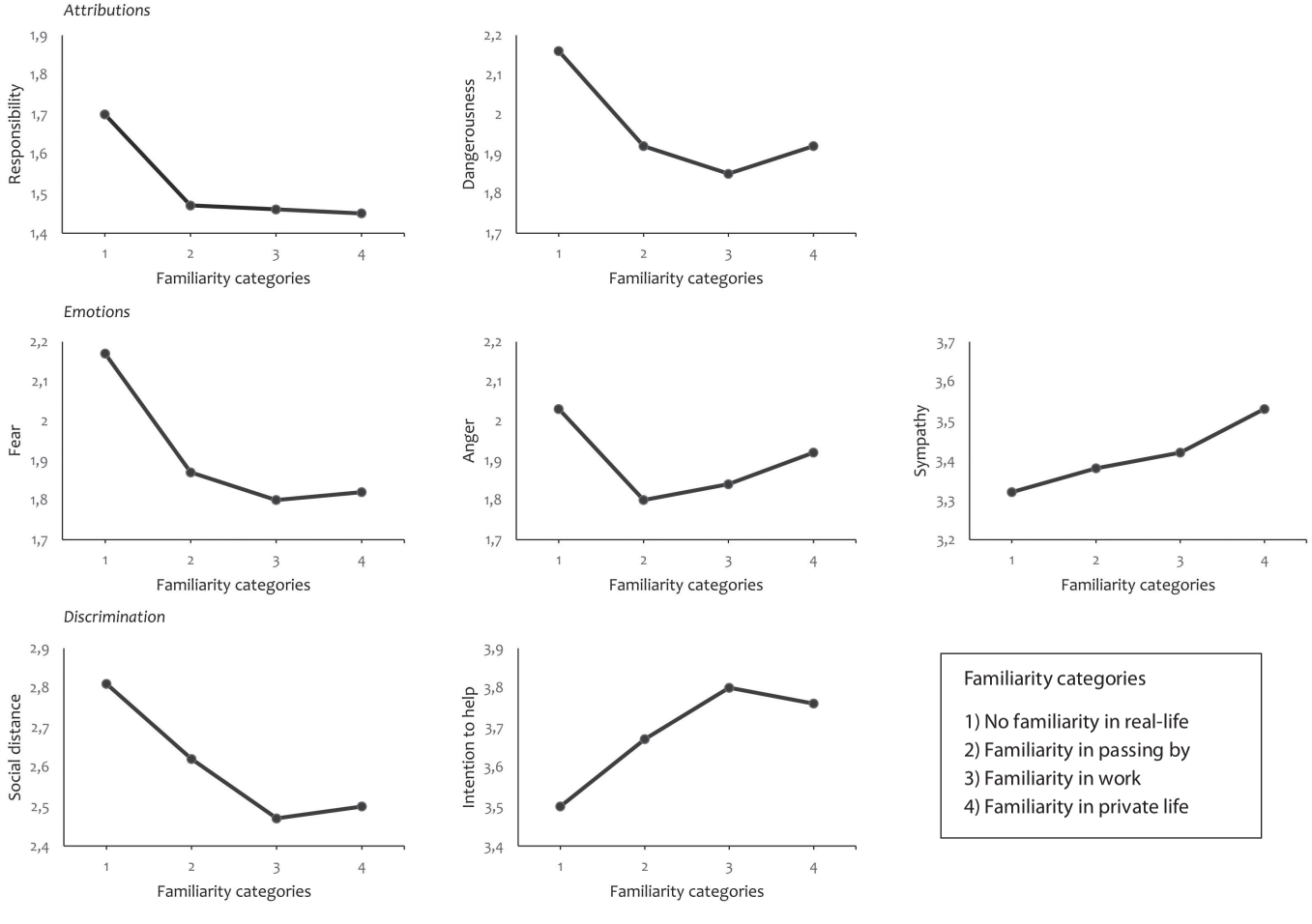

FIGURE 2 | Descriptive plots of familiarity categories related to stigma measures.
Note that in all graphs, the estimated means of outcome variables are scaled with a 0.5 score total distance.

Finally, the only exception concerned the emotion 'sympathy'. Figure 2 shows a reversed trend in the descriptive plot (i.e., visually, the category 'familiarity in private life' seems to deviate from the other categories; this is opposed to the other variables where, visually, the category 'no familiarity in real-life' seems to deviate from the other categories). Corresponding with the visual exploration, a difference contrast (i.e., 4 – 1, 2, 3; 3 – 1, 2; 2 – 1) for this variable was conducted as opposed to the latter Helmert contrast (i.e., 1 – 2, 3, 4; 2 – 3, 4; 3 – 4). This difference contrast supported the visual exploration in that it showed that respondents in the category 'familiarity in private life' scored significantly higher on sympathy as compared to the other three categories of familiarity (M_{dif} = 0.154 (0.051), t (3) = 3.063, p =.002). No significant differences were found for the other contrasts.

TABLE 3 | *Helmert Contrasts between different Categories of Familiarity on Stigma Measures.*

	M_{dif}	SE	t	p
Responsibility				
1 – 2, 3, 4	0.235	.046	5.11	<.001
2 – 3, 4	0.012	.053	0.23	.821
3 – 4	0.010	.071	0.14	.885
Dangerousness				
1 – 2, 3, 4	0.265	.048	5.52	<.001
2 – 3, 4	0.037	.046	0.80	.509
3 – 4	-0.070	.076	-0.92	.354
Fear				
1 – 2, 3, 4	0.343	.052	6.60	<.001
2 – 3, 4	0.056	.060	0.93	.351
3 – 4	-0.025	.081	-0.31	.759
Anger				
1 – 2, 3, 4	0.176	.048	3.67	<.001
2 – 3, 4	-0.078	.055	-1.42	.161
3 – 4	-0.076	.075	-1.01	.311
Sympathy[1]				
4 – 1, 2, 3	0.154	.051	3.02	.002
3 – 1, 2	0.064	.075	0.85	.395
2 – 1	0.058	.060	0.97	.333
Social Distance				
1 – 2, 3, 4	0.274	.055	4.98	<.001
2 – 3, 4	0.137	.064	2.14	.031
3 – 4	-0.029	.086	-0.34	.739
Intention to help				
1 – 2, 3, 4	-0.241	.045	-5.36	<.001
2 – 3, 4	-0.110	.053	-2.08	.037
3 – 4	0.049	.071	0.69	.492

Note. [1]Given the descriptive plot of sympathy (Figure 2), a difference contrast for this variable was conducted. This resulted in a significant deviation of 'familiarity in private life' with the other categories of familiarity (M_{dif} = 0.154 (0.051), t (3) = 3.063, p =0.002).

MEDIATION ANALYSES

Emotions as a mediator between familiarity and discrimination

We conducted mediation analyses using structural equation modelling to examine whether emotions of participants (i.e., fear, anger, sympathy) may mediate the relationship between familiarity (i.e., four categories) and discrimination (i.e., social distance and intention to help). Because familiarity is a multi-categorical predictor with four levels, we followed the strategy as proposed by Hayes and Preacher (2014) in which indicator coding is used (Hayes & Preacher, 2014). That is, we examined the relative effect of the level of familiarity on emotions and discrimination using 'no familiarity in real-life' as the reference category. The other categories were represented as three dummy variables: D1 = 'familiarity in passing by'; D2 = 'familiarity in work'; D3 = 'familiarity in private life' (see Addendum for the model and the Mplus syntax). Following, the results of the mediation analysis are presented (see Figure 1).

Emotions as mediator in the relationship between familiarity and social distance

First, the analyses showed that relative to the category 'no familiarity in real-life', the three categories of familiarity were not directly related to levels of social distance when emotions were taken into account. However, the sum of indirect effects (i.e., for every dummy variable/ category of familiarity, the sum of the indirect effects of fear, anger, and sympathy) was significant, indicating that emotions seemed to mediate the relationship between familiarity and social distance for all three categories of familiarity relative to the category 'no familiarity in real life' (i.e., D1 b = -0.144, bias-corrected 95% C.I. = [-0.245, -0.055]; D2 b = -0.177, bias-corrected 95% C.I. = [-0.305, -0.048]; D3 b= -0.231, bias-corrected 95% C.I. = [-0.333, -0.142). To further explore the mediation effect of emotions, we examined the specific indirect effects for each emotion separately.

Sympathy

Sympathy accounted for the relationship between 'familiarity in private life' and social distance: b = -0.114 (0.041) bias-corrected 95% C.I = [.-0.196, -0.042]. That is, relative to the reference category, participants who reported 'familiarity in private life' reported a .114 units lower score on social distance as a result of the positive (mediation) effect of sympathy on reducing social distance, when controlling for levels of anger and fear. This mediation effect of sympathy was not found for the categories 'familiarity in passing by' and 'familiarity in work'.

Fear

Relative to the category 'no familiarity in real-life', fear was a significant mediator of the relationship between all three categories of familiarity on the one hand and social distance on the other hand: D1 b = -0.087 (0.023) bias-corrected 95% C.I. = [-0.144, -.050]; D2 b = -0.104 (0.034) bias-corrected 95% C.I. = [-0.180, -0.050]; D3 b = -0.101 (0.025), bias-

corrected 95% C.I. = [-0.154, -0.060]. This means that, 'familiarity in passing by', 'familiarity in work' and 'familiarity in private life' predicted lower levels of fear relative to the 'no familiarity in real-life' category. These lower levels of fear in turn predicted lower levels of social distance.

Anger

Concerning the emotion of anger, effects similar to those of fear were found, but for anger the effects were smaller (negligible) and only on the border of significance: D1 b = -0.026 (0.013) bias-corrected 95% C.I. = [-0.059, -.005]; D2 b = -0.027 (0.015) bias-corrected 95% C.I. = [-0.066, -0.007]; D3 b = -0.017 (0.009), bias-corrected 95% C.I. = [-0.040, -0.003].

To summarise the mediation effect of emotions in the relationship between familiarity and social distance, fear seems to be the strongest mediator of the relationship between familiarity and social distance. Sympathy seems to mediate the relationship between familiarity and social distance only for 'familiarity in private life' relative to 'no familiarity in real-life'. Anger seems to be a significant but negligible mediator of the relationship between familiarity and social distance.

Emotions as a mediator in the relationship between familiarity and intention to help

We conducted a mediation analysis similar to the latter analysis with social distance as an outcome variable, to examine whether emotions (i.e., fear, anger, sympathy) may mediate the relationship between familiarity and the intention to help. The analyses showed results similar to those for social distance, only with smaller effects. First, relative to the category 'no familiarity in real-life', only the category 'familiarity in work' was directly related to higher levels of intention to help when emotions were taken into account: D2 b = 0.151 (0.069), p = .028. For all three categories of familiarity the sum of the indirect effects (i.e., the sum of the indirect effect of fear, anger, and sympathy) was significant, indicating that emotions seem to mediate the relationship between familiarity and the intention to help for all three categories of familiarity relative to the category 'no familiarity in real-life': D1 b = 0.127, bias-corrected 95% C.I. = [0.047, 0.214]; D2 b = 0.153, bias-corrected 95% C.I. = [0.040, 0.267]; D3 b= 0.197, bias-corrected 95% C.I. = [0.120, 0.288. To further explore the mediation effect of emotions, we examined the specific indirect effects for each emotion separately.

Sympathy

Sympathy accounted for the relationship between 'familiarity in private life' and the intention to help: b = 0.097 (0.034) bias-corrected 95% C.I = [0.035, 0.169]. That is, relative to the control condition, participants who reported 'familiarity in private life' reported a .097 units higher score on intention to help as a result of the positive (mediation) effect of sympathy on increasing the intention to help, when controlling for levels of anger and fear. This mediation was not found for the categories 'familiarity in passing by' and 'familiarity in work'.

Fear

Relative to the category 'no familiarity in real-life', fear was a significant mediator of the relationship between all three categories of familiarity on the one hand and the intention to help on the other hand: D1 b = 0.070 (0.019) bias-corrected 95% C.I. = [0.038, 0.115]; D2 b = 0.084 (0.026) bias-corrected 95% C.I. = [0.041, 0.142]; D3 b = 0.081 (0.019), bias-corrected 95% C.I. = [0.052, 0.128]. This means that, 'familiarity in passing by', 'familiarity in work' or 'familiarity in private life' predicted lower levels of fear relative to the category of 'no real-life familiarity', these lower levels of fear in turn predicted a higher intention to help.

Anger

Concerning the emotion of anger, similar effects as for fear were found, but for anger the effects were smaller (negligible), and only on the border of significance: D1 b = 0.029 (0.011) bias-corrected 95% C.I. = [0.011, 0.058]; D2 b = 0.030 (0.014) bias-corrected 95% C.I. = [0.010, 0.068]; D3 b = -0.019 (0.009), bias-corrected 95% C.I. = [0.006, 0.047].

To summarise the mediation effect of emotions in the relationship between familiarity and the intention to help, fear seems to be the strongest mediator of the relationship between familiarity and intention to help. Sympathy seems to mediate the relationship between familiarity and the intention to help only for 'familiarity in private life' relative to 'no familiarity in real-life'. Anger seems to be a significant but negligible mediator of the relationship between familiarity and intention to help.

DISCUSSION

In this study we have examined the Dutch general public's levels of familiarity with people with intellectual disabilities, its relationship with stigma and the mediating role of emotions in this relationship. The present study demonstrated that two-thirds of the Dutch population reported familiarity with people with intellectual disabilities in any form, while one third reported no real-life familiarity. In general, relatively low levels of stigma were reported in this study. Nevertheless, members of the general public who were unfamiliar with people with intellectual disabilities in real life, demonstrated higher levels of stigmatisation than people who reported some form of real-life familiarity. People who reported familiarity within their private lives reported higher levels of sympathy than people who reported less familiarity. When emotions were taken into account, no direct effects of familiarity on levels of discrimination were found. Yet, emotions mediated the relationship between familiarity and discrimination, among which fear was found to be the strongest mediator. That is, being more familiar with people with intellectual disabilities predicted lower levels of fear towards them, which in turn predicted lower levels of discrimination. Concerning sympathy, a mediation effect was only found for people who reported familiarity in private life whereby higher levels of sympathy explained lower social distance and more intention to help.

Our study has demonstrated that the number of people who are unfamiliar with people with intellectual disabilities within the Dutch population (about a third) is still substantial. This is especially relevant in light of the finding that participants with no familiarity in real life reported higher levels of stigmatisation. The relationship between familiarity and stigmatisation is also demonstrated within population studies in the field of mental illness (Angermeyer & Dietrich, 2006). Moreover, recent studies in the field of intellectual disabilities demonstrated that prior contact with people with intellectual disabilities related to lower levels of stigmatisation (Blundell et al., 2016; Werner, 2015; Wilson & Scior, 2015). Therefore, policy makers should be aware that mere physical integration does not automatically lead to a situation in which people with intellectual disabilities are known and recognised within mainstream society. Raising awareness of this finding among policy makers might increase a sense of urgency to adhere to the United Nations convention on the rights of persons with disabilities, which, as a consequence, could increase the support for developing innovative policies and laws that create space for people with intellectual disabilities to realise valuable life goals. For example, it may prove beneficial to involve advocacy groups of people with intellectual disabilities on a more structural basis in the development of policies that affect the lives of people with intellectual disabilities on a local, national, and organizational level.

Concerning public anti-stigma interventions, these results support a focus on increasing the general public's familiarity with people with intellectual disabilities. After all, participants in the present study who only reported 'familiarity in passing by' already showed lower levels of stigmatisation than people reporting no familiarity in real life. In line with this, Bigby and Wiesel (2019) suggest that within mainstream society 'convivial encounters' may help people with intellectual disabilities to 'being recognised' and 'becoming known' (Bredewold, Tonkens, & Trappenburg, 2016; Goffman, 1961; Wiesel & Bigby, 2014). These convivial (i.e., fleeting or more sustained) encounters in daily live with for example neighbours, shopkeepers, and bus-drivers may provide a potential space for the general public to become familiar with people with intellectual disabilities (Bigby & Wiesel, 2015; 2019). Suggestions on how support workers may promote convivial encounters between their clients and people from mainstream society, are presented by Bigby and Wiesel (2019). For example, support workers could initiate such encounters.

However, it is far from evident that support workers play a role in advocating for people with intellectual disabilities. In the Netherlands, one of the key foci within support is individualised support planning which is a legal requirement for service organizations as a way of enhancing person-centred support and high quality care. That is, people with intellectual disabilities together with their legal representatives/relatives and support workers should agree on goals for individual support along the lines of quality-of-life indicators (Herps, Buntinx, Schalock, Van Breukelen, & Curfs, 2016). However, such a strong focus on individual support planning, risks overlooking a structural line along which support

workers are motivated to focus on the structural, societal context in which people with intellectual disabilities live. Moreover, it risks overlooking attention for how to advocate for their clients and challenge stigma. Furthermore, previous studies have shown that support workers' perceptions of a professional role identity primarily focused on care tasks and not on promoting social inclusion (Overmars-Marx, 2018). Therefore, support workers may form a potential source of advocacy that is not fully used as this aspect of social care roles has not been recognised well. In addition to providing and arranging individualised support, support workers should be encouraged and facilitated to cooperate with local government and local communities to advocate for people with intellectual disabilities, increase familiarity and combat existing stigma. Also, in training programs it seems to be relevant to pay attention to motivating support workers to support encounters within mainstream society (e.g., providing them with good practices). Whenever possible, support workers should empower people with intellectual disabilities to play a role in this process of advocacy themselves. In the Dutch context this is needed both in the long-term intensive care context, as well as in the context of social support.

Moreover, professionals that can play a key role towards full inclusion (e.g., employers, health professionals, and policy advisors) could be specifically targeted in anti-stigma interventions. That is, members of the general public with no familiarity in real life with people with intellectual disabilities, may include people that can play a key role in facilitating full inclusion as professionals such as mainstream health professionals, employers, policy makers (Ellenkamp, Brouwers, Embregts, Joosen, & van Weeghel, 2015; Pelleboer-Gunnink, Van Oorsouw, Van Weeghel, & Embregts, 2017). These groups can be offered education about intellectual disabilities taught by trained advocates with lived experience of intellectual disabilities. This may induce a potentially positive contact experience (Kienhorst, Pijnenborg, & van Weeghel, 2016). Future studies might investigate the effect of stimulating convivial encounters within mainstream society as well as the effect of targeting key professionals, on population levels of familiarity and related stigmatisation of people with intellectual disabilities.

The present study showed that emotions seem to mediate the relationship between familiarity and discrimination. Specifically, fear, compared to sympathy and anger, seemed to be the most apparent mediator. This aligns with stigma research following from the intergroup contact theory. Pettigrew and Tropp (2006) discuss in a meta-analysis that especially reducing intergroup anxiety can achieve reductions in stigmatisation following from contact (Paolini et al., 2004). In their discussion, intergroup anxiety refers to feelings of threat and uncertainty that grow out of concerns about how one should act, how one might be perceived and whether one will we accepted. Also, in the field of intellectual disabilities, there are indications that fear and anxiety may play a role in establishing reactions towards people with intellectual disabilities (Pelleboer-Gunnink et al., 2017; Scior, Connolly, et al., 2013). Thus, it seems reasonable to assume that, concerning people with intellectual disabilities, increased positive outcomes of anti-stigma contact interventions

could be achieved to the extent that anxiety (as can be induced by fear) is reduced (Pettigrew & Tropp, 2006). Future intervention studies should consider incorporating measures of anxiety to further explore if and how contact interventions affect levels of anxiety concerning people with intellectual disabilities, and to explore whether decreasing anxiety might improve intervention outcomes.

Finally, we have to note that in comparison to results presented in the field of mental illness, this study, reported relatively low mean levels of explicit stigmatisation among the general public (e.g., compare to Corrigan et al., 2002; Pescosolido, Medina, Martin, & Long, 2013; Pescosolido et al., 2010). Correspondingly, in a study comparing general public's responses towards people with schizophrenia and intellectual disabilities, intellectual disabilities were related to lower levels of stigma than schizophrenia (Scior, Potts, & Furnham, 2013). However, although people with intellectual disabilities might be less stigmatised in the sense of harsh exclusion, they might be more stigmatised in terms of paternalistic attitudes/stigmatisation due to low attributed responsibility and dangerousness and high levels of sympathy and intention to help (Corrigan, 2017; Ditchman et al., 2013; Fiske, 2012). Also, there is vast heterogeneity in the group of people with intellectual disabilities. Studies using vignettes describing people with mild intellectual disabilities presented higher levels of explicit stigmatisation than studies, this study included, that provided the label 'intellectual disabilities' (Scior, Connolly, et al., 2013; Scior, Potts, et al., 2013). Thus, continuing research is needed to unravel the complex process of stigmatisation of people with intellectual disabilities. Such research should draw on existing stigma measures and theories. More specifically, future research should develop tailored measures that may focus on paternalistic forms of stigmatisation specifically designed for intellectual disabilities.

LIMITATIONS AND STRENGTHS

One of the main strengths of this study was the use of a high quality population sample with a good response rate, which, to our knowledge, has hardly been used before in intellectual disabilities stigma research. As a result, the results provide descriptive information on population level. One of the main limitations of this study concerns the exclusively descriptive and cross-sectional nature of the results. Experimenting with different vignettes or different levels of intellectual disabilities could have provided more insights into the constituents of the intellectual disabilities stigma (van Alphen, Dijker, Bos, Borne, & Curfs, 2012; Scior, Connolly, et al., 2013). The findings of this study provide fundamental insight into people's reaction to the plain label 'intellectual disabilities' without any explanation or confounding with other variables. However, due to the absence of explanation about the definition of intellectual disabilities, there is a risk that the higher stigma scores for the unfamiliar participants might be explained by an incorrect interpretation of the term 'intellectual disabilities' (e.g., as mental illness). Moreover, to make use of validated measures compatible with existing concepts of stigma, most

measures have been borrowed from the field of psychiatry (Ditchman et al., 2013). Yet, to capture the stigma of people with intellectual disabilities, additional measures might need to be developed that demonstrate more variability and might relate to paternalistic forms of stigmatisation (i.e., issues relating to restrictions in self-determination, choice, and autonomy) (Brockington, Hall, Levings, & Murphy, 2000; Corrigan, Watson, Byrne, & Davis, 2005). Finally, one of the subscales of emotions (i.e., sympathy) demonstrated a lower than acceptable Cronbach's alpha (.624) which might have been caused by the small number of items addressing this emotion (n =2). This low internal reliability might have weakened the associations of this scale with other variables.

CONCLUSION

Even though people with intellectual disabilities are living in mainstream society more often, the challenge of going beyond physical integration towards full inclusion remains. Reducing stigmatisation may provide a crucial strategy in the drive towards full inclusion. This study has shown that a third of the Dutch general population does not report any familiarity with people with intellectual disabilities in real-life which, consequently, related to higher levels of stigma. This finding stresses the importance to collectively advocate for people with intellectual disabilities in order for them to be recognised and become known within society. Support workers may play a vital role in this process. Moreover, the importance of fear in the relationship between familiarity and discrimination, may direct future research and interventions to address this emotion. This may facilitate easy and comfortable encounters between people with and without intellectual disabilities.

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Chapter 4

People with intellectual disabilities as compared to the general public: an exploratory cross-sectional study into stereotypes

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ABSTRACT

Background
Public stereotypes may undergird people with intellectual disabilities' experiences of stigma. This study explored which assigned characteristics distinguish people with intellectual disabilities from the general public (i.e., stereotypes).

Method
In a stratified convenience sample (n = 194) from the Dutch general public, participants judged personal attributes of people with intellectual disabilities and the general public by providing likelihood ratings for both groups on 22 characteristics. Familiarity was studied as a moderator.

Result
Strongly stereotypical characteristics focused on dependency and incompetence, and strongly counter-stereotypical characteristics focused on competence and independence. Friendly characteristics were found stereotypical but with a smaller effect size; nuisance characteristics were found not (strongly) stereotypical.

Discussion
In previous studies, the demonstrated stereotypes of incompetence and dependency have found to be poorly related to common discrimination measures for people with intellectual disabilities (e.g., social distance). Therefore, future research should thoroughly explore the nature of discrimination that is related to these stereotypes.

People with intellectual disabilities experience stigmatisation within society (Giesbers, Hendriks, Jahoda, Hastings, & Embregts, 2018). For example, many of them feel being treated as children, being stared at, being called names, or viewed as stupid (Ali, Hassiotis, Strydom, & King, 2012; Ali, Strydom, Hassiotis, Williams, & King, 2008; Jahoda, Wilson, Stalker, & Cairney, 2010). Public stereotypes about the group of people with intellectual disabilities may undergird these stigmatising experiences (Biernat & Dovidio, 2000). Previous studies have, for example, demonstrated that the general public judges people with intellectual disabilities as friendly people, who are in need of help, and not competent to act on their intentions (Fiske, 2012; Gilmore, Campbell, & Cuskelly, 2003; Werner, 2015). Such stereotypes might express itself in paternalising or even negative behaviours, which may strain people's opportunities to realise valuable life goals such as having employment, stable social relationships, or good health (Emerson, 2007; Tuffrey-Wijne et al., 2014).

A stronger knowledge base into intellectual-disabilities stereotypes is needed to enable the development of anti-stigma initiatives related to people with intellectual disabilities (United Nations, 2006). However, the studies that have been conducted on this subject so far, are limited in number, scope, and methodology (Pelleboer-Gunnink, van Weeghel, & Embregts, 2019; Scior, 2011). Particularly, researchers have studied public stereotypes of people with intellectual disabilities by using Likert scales to ask participant's agreement with statements about people with intellectual disabilities (e.g., "People with intellectual disabilities are friendly", Likert response: "totally disagree – totally agree"). The use of Likert scales has provided significant insights such as the public attribution of the stereotypes *being friendly*, *being in need of help*, and *being incompetent* to the group of people with intellectual disabilities (Pelleboer-Gunnink et al., 2019; Werner, 2015). These insights enable further exploration of the consequences of these stereotypes. However, Likert-scale studies, asking about people's agreement with a single statement, cannot represent the probabilistic nature of stereotypes. That is, stereotypes are seen as probabilistic beliefs about characteristics that distinguish one group from another (Eyal & Epley, 2017). Within Likert-scale studies, this comparison with the general public has not been made.

In this paper, we aimed to gain new insights into the stereotyping of people with intellectual disabilities by piloting the percentage-technique. Because familiarity with a minority group is one of the main buffers against stigma (Pettigrew & Tropp, 2006), we have additionally examined the relationship between the strengths of assigned stereotypes and the levels of familiarity of participants with people with intellectual disabilities. In a stratified convenience sample, we explored which assigned characteristics distinguish people with intellectual disabilities from the general public (i.e., stereotypes). Thereby, we further validate stereotypes that have been found to date, and we gain insight which of these stereotypes are the most distinctive for people with intellectual disabilities as compared to the general public.

METHOD

Exploratory Cross-sectional Design

A total number of 194 Dutch speaking members of the general public participated in this cross-sectional survey in 2017 in the Netherlands. A stratified convenience sampling method was used. This study received ethical approval from the Ethics Review Board of Tilburg University (EC-2016.60).

Participants

Two inclusion criteria were applied: first, participants needed to be Dutch speaking (i.e., the main national and official language in the Netherlands), second, participants needed to be 18 years or older. Stratification was applied based on age and gender according to Dutch population statistics (Statistics Netherlands, 2015). In the recruited sample, men aged 20-40 years were slightly over-represented and elderly >65 years of age were slightly under-represented. In addition, people with low education were under-represented and people with middle and high education were overrepresented.

Procedure

We have recruited participants in the city centres of three cities (between 160.000-334.000 residents) in three different provinces in the Netherlands. The intended sample size was 176 participants (i.e., with a medium effect size and $\alpha = .05$, a power of .95 is obtained for all analyses with a sample size of ≥ 176 participants). Participants who were willing and eligible (>18 years of age; Dutch-speaking) to participate, were explained both the aim of the study and about the informed consent. Participants filled out both the informed consent and questionnaire (5-10 minutes) on the spot. They received a debriefing letter after finishing the questionnaire.

Measures

Stereotypes

When aiming to take the probabilistic nature of stereotypes into account, a percentage technique could be a suitable approach. Using this approach might therefore improve the construct validity in the measurement of stereotypes of people with intellectual disabilities (Stephan et al., 2014). The percentage technique provides a description of characteristics that are believed to be connected with a greater likelihood to either a target group (i.e., stereotypical) or to a reference group (i.e., counter-stereotypical) (Martell & DeSmet, 2011; Stephan et al., 2014). Similar as with Likert scales, participants are given a list of attributes. However, consequently, they are asked to make two percentage estimates instead. One estimate of the percentage of the target group (e.g., people with intellectual disabilities) that has each attribute, and one estimate of the percentage of the reference group (e.g., general public) that has each attribute (e.g., 'What percentage of people with intellectual

disabilities/the Dutch general public is friendly?' Response 0-100%). This method (and also the closely related diagnostic ratio approach) has been used in research into gender and ethnic stereotypes, but not yet concerning people with intellectual disabilities (e.g., Block, Aumann, & Chelin, 2012; Martell & DeSmet, 2011; Stephan et al., 2014). As an alternative, the diagnostic ratio approach is closely related (e.g., Block, Aumann, & Chelin, 2012; Martell & DeSmet, 2011). However, the percentage method has been demonstrated to show higher reliability and validity as compared to the diagnostic ratio approach and is, therefore, used in this study (Biernat & Crandall, 1996; Stephan et al., 2014).

We thus used a percentage technique to assess stereotypes in this study. Stereotype items (n = 22) were derived from a previous study (Pelleboer-Gunnink et al., 2019). Pelleboer-Gunnink and colleagues developed an item-list based on literature and a pilot study. Moreover, they provided input for additional items by analysis of an open-ended question asked to a random sample of 892 Dutch citizens. Based on salient stereotypes in the latter open question, we have added four items (i.e., 'is independent', 'is socially skilled', 'is unrestrained', 'is slow') to the present study that were not yet represented in the original list of stereotype items. The response format used to answer the percentage questions was an 11-point scale marked in increments of 10 percentage points. A random counterbalanced design was used in which half of the participants first answered the questions about the general public followed by the questions about people with intellectual disabilities and vice versa as to correct for a possible order effect.

Level of Contact Report – familiarity

The Level of Contact Report (Holmes, Corrigan, Williams, Canar, & Kubiak, 1999), a measure found to be valid and reliable when concerning familiarity with mental illness, was used to assess the degree of familiarity that participants have with people with intellectual disabilities(Corrigan et al., 2001; Holmes, et al., 1999). On a 12-item list participants had to check the situations that best depicted their exposure to people with intellectual disabilities. For example, "I have worked with a person who had an intellectual disability at my place of employment". The degree of familiarity was the most familiar situation that was indicated by the participant. Due to non-normally distributed rank scores, we made four categories based on the content of the items. The categories indicated: 'no familiarity in real-life' (rank-item 1–4, e.g., watching a documentary), 'familiarity in passing by' (rank item 5, i.e., observing people on a frequent basis), 'familiarity in work' (rank-item 6–8, e.g., providing services), and 'familiarity in private life' (rank-item 9–12, e.g., friend of the family).

Analyses

First, potential order effects for the stereotype items concerning the general public and people with intellectual disabilities were studied with independent t-tests on the difference scores with a Bonferroni correction. In case of a significant order effect, this stereotype was not used in consequent analyses. Following, paired-t-tests were used to assess significant differences between percentages of the general public and people

with intellectual disabilities that were assigned certain characteristics. The influence of familiarity on the strength of the stereotypes was assessed by conducting a Multivariate Analysis of Covariance (MANCOVA) with the version of the questionnaire, gender, and age as covariates, the mean difference score for each stereotype item as dependent variables, and familiarity as an independent variable.

RESULTS

Prior to analyses of the stereotype percentages, data were screened to explore whether the data (interval variables) met the assumption of normal distribution. Kurtosis (max. = 3.561) and Skewness (max. = 1.718) of all variables were within the range of ± 7 and ± 2, respectively. Therefore, the data were assumed to be normally distributed (Kim, 2013)(Kim, 2013). Also, analyses were conducted to explore whether order effects were found, yet these effects were not significant. Therefore the order in which the questions were presented (first general public, or first people with intellectual disabilities) did not significantly affect the results and there was no need to correct for this effect.

Stereotypes

Results of the paired-samples *t*-tests, and descriptive statistics of the percentage scores are presented in Table 1 and are ordered according to effect size. Looking into stereotypes with a large effect size (Cohen's $d > 0.80$), a larger percentage of people with intellectual disabilities compared to people in the general public were judged to have 'difficulty learning', 'difficulty functioning in society', and to be 'in need of help', 'childlike', 'slow', 'vulnerable', 'affectionate', and 'unrestrained' (i.e., stereotypical). Meanwhile, also with a large effect size, a smaller percentage of people with intellectual disabilities as compared to the Dutch general public is judged to be 'independent', 'able to work in a paid position', 'socially skilled', or 'intelligent' (i.e., counter-stereotypical). Most of these (counter-) stereotypes seem to involve some form of incompetence and dependence concerning people with intellectual disabilities. .Characteristics that refer to 'warm stereotypes' (Pelleboer-Gunnink et al., 2019) were not significant ('sociable'), or were found to be significant with a small ('happy', 'are to be trusted') or medium effect size ('friendly'). For the characteristics 'nuisance', 'sociable' and 'can be aggressive', no significant differences were found on the percentages assigned to the Dutch general public or people with intellectual disabilities. Thus, these characteristics were neither stereotypical nor counter-stereotypical.

TABLE 1 | *Descriptive statistics and results of paired-samples t-tests of stereotypes assigned to people with intellectual disabilities versus the general public*

Stereotypes	People of the Dutch general public (%)		People with intellectual disabilities (%)		*t (193)*	*p*	ES
Stereotypical	*M*	*SD*	*M*	*SD*			
… has difficulty learning	**33.66**	**13.75**	**69.23**	**19.21**	**-19.82**	**< .001**	**2.13**
… has difficulty functioning in society	**28.35**	**15.48**	**59.59**	**20.15**	**-18.84**	**< .001**	**1.74**
… is in need of help	**31.03**	**16.76**	**64.07**	**21.24**	**-17.46**	**< .001**	**1.73**
… is childlike	**26.86**	**16.82**	**52.58**	**22.84**	**-13.98**	**< .001**	**1.28**
… is slow	**29.95**	**14.60**	**52.22**	**20.23**	**-14.24**	**< .001**	**1.27**
… is vulnerable	**42.94**	**24.43**	**71.86**	**21.37**	**-14.40**	**< .001**	**1.26**
… is affectionate	**37.68**	**18.44**	**59.69**	**19.26**	**-13.37**	**< .001**	**1.17**
… is unrestrained	**35.21**	**19.53**	**53.04**	**23.49**	**-9.28**	**< .001**	**.83**
… is friendly	67.06	14.33	75.82	13.14	-6.89	< .001	.64
… neglect him/herself	24.43	15.20	35.46	21.01	-6.65	< .001	.60
… is looking physically different	41.08	33.51	58.30	28.52	-7.17	< .001	.55
… is happy	63.97	14.33	70.93	15.07	-5.34	< .001	.47
… is to be trusted	61.44	19.92	66.75	20.54	-3.17	≤ .002	.26
… is sad	19.95	15.15	23.81	18.88	-2.78	.006	.23
… is sociable	64.07	15.08	66.08	16.73	-1.48	.141	.13
… can be aggressive	40.93	22.07	43.40	23.61	-1.46	.146	.11
Counter-stereotypical							
… is independent	**68.56**	**15.51**	**38.04**	**17.04**	**19.89**	**< .001**	**1.87**
… is able to work in a paid position	**79.12**	**13.34**	**50.41**	**20.83**	**19.13**	**< .001**	**1.64**
… is socially skilled	**67.01**	**14.08**	**47.63**	**18.05**	**12.93**	**< .001**	**1.20**
… is intelligent	**56.65**	**16.96**	**39.74**	**21.14**	**10.33**	**< .001**	**.88**
… is criminal	20.88	15.43	15.82	12.70	3.87	< .001	.36
… is a nuisance	27.37	18.12	24.85	15.81	1.83	.069	.15

Note. The effect size concerns Cohen's *d* and is evaluated as >0.2 = small; >0.5 = medium; >0.8 = large (NB bold-faced).

Familiarity

People who reported no familiarity in real life with people with intellectual disabilities were a minority in the sample (i.e., 13.4%). A quarter of the participants (24.2%) were familiar with people with intellectual disabilities in 'passing by', and a quarter (23.7%) was familiar in a work context. A large percentage of the participants (38.7%) were familiar with a person with intellectual disabilities in the private context (e.g., a friend of the family). Compared to a population study in the Netherlands exploring familiarity with people with intellectual disabilities, participants with no familiarity in real life were underrepresented in this study (30.6% in population study) (Pelleboer-Gunnink, van Oorsouw, van Weeghel, & Embregts, 2020).

Levene's test was, with a Bonferroni correction (dividing the original alpha by the number of tests, leads to the use of an alpha of .002), non-significant for all stereotype difference

scores, thereby supporting the tenability of the assumption of homogeneity of variances (i.e., range: $p = .015$ and $p = .969$). No statistically significant multivariate effect of category of familiarity of participants on the strength of the stereotypes was found, corrected for the effects of gender, age, and version of the survey ($\Lambda = .692$, F (66, 494) = .981, $p = .523$).

DISCUSSION

People with intellectual disabilities report experiences of stigma within society. Public stereotypes about people with intellectual disabilities may undergird these experiences. In the present study, a stratified convenience sample of the Dutch general public was used to explore which assigned characteristics distinguish people with intellectual disabilities from the general public (i.e., stereotypes) according to the general public. To do so, we have used a percentage technique to assess stereotypes of people with intellectual disabilities in order to extend the often-used Likert-scales. Characteristics that were found strongly stereotypical for people with intellectual disabilities mostly involved areas of dependency and incompetence (e.g., 'have difficulty learning', 'are in need of help', 'are slow', 'are vulnerable'). Similarly, characteristics that were strongly counter-stereotypical concerned stereotypes of competence and independence (e.g., 'are independent', 'are able to work in a paid position'). Warm and friendly characteristics were found stereotypical but less strong than the incompetent characteristics. Characteristics referring to people with intellectual disabilities as a nuisance were not (strongly) stereotypical. No relationship between levels of familiarity with people with intellectual disabilities and the strength of stereotypes was found in this study.

Even though these results need to be interpreted with caution due to the preliminary nature of the study, the results prompt us to think about their potential meaning, both concerning the use of the percentage technique as well as concerning the nature of stigma and the use of anti-stigma strategies. Concerning the use of the percentage technique, one finding that indicates a benefit of this method over Likert-scale studies is the demonstrated minor distinctiveness of stereotypes that refer to characteristics such as warm and friendly. In previous studies using Likert-type scales, stereotypes that refer to people with intellectual disabilities as warm or friendly, were considered to be "main stereotypes" (i.e., characteristics with high mean scores; Fiske, 2012; Pelleboer-Gunnink et al., 2019; Werner, 2015). This study showed that even though a large percentage of people with intellectual disabilities were viewed as warm and friendly, a large percentage of the general public were viewed as warm and friendly as well. Warm and friendly characteristics might thus not be strongly distinguishing characteristics; this deviates from what the results of previous Likert-scale studies seem to suggest. Summarised, results derived from the percentage technique represent the probabilistic nature of stereotypes more accurately and thereby extend existing studies that do not make comparisons with the general public (Martell & DeSmet, 2011; Stephan et al., 2014).

Concerning stereotypes of clearly negative behaviours ('can be aggressive', 'criminal', 'a nuisance'), the present results are similar to previous studies in that these stereotypes were found to be either counter-stereotypical or non-significant. That is, people with intellectual disabilities are expected to be less criminal than the Dutch general public and similar to the Dutch general public on levels of nuisance or potential aggression. This coincides with the low mean scores on alike stereotypes using Likert-scales in previous studies, and thus adds to the construct validity former measures (Pelleboer-Gunnink et al., 2019; Werner, 2015). Studies addressing memory biases (e.g., accentuation bias or recall bias) have stressed the fact that especially information/experiences that accord with the core of our stereotypes is processed and recalled stronger than information that does not belong to the core of our stereotypes (Fyock & Stangor, 1994). Therefore, probably, experiences of aggression/nuisance concerning people with intellectual disabilities, might not be recalled strongly by the general public even though these experiences may take place (Matson & Shoemaker, 2011).

Concerning the potential implications of this study related to the nature of stigma and anti-stigma interventions, a first line of thought relates to the prominence of stereotypes that refer to people with intellectual disabilities as incompetent, dependent, vulnerable, and childlike as found in this study. In previous Likert-type studies, alike stereotypes were found (Pelleboer-Gunnink et al., 2019; Werner, 2015). This study underlines and extends these results by showing that people with intellectual disabilities seem to deviate the most from the general public on these characteristics. However, these stereotypes have been demonstrated in previous studies to have little to no predictive value concerning regular measures of discrimination (i.e., social distance, intention to help). That is, the stereotypes of 'warmth' and 'dangerousness' have been found to be more predictive of discrimination (i.e., social distance and intention to help) than stereotypes of incompetence (Pelleboer-Gunnink et al., 2019; Werner, 2015). Yet, the evidence is clear that people with intellectual disabilities are challenged by stigma both in how they are treated as well as in structural stigma that limits their opportunities to realise valued life goals. Because these incompetent/dependent stereotypes play a significant role in the stigma of people with intellectual disabilities, a main task of future research is to explore the nature of discrimination that may be related to these stereotypes, and as well, to develop discrimination measures accordingly (Werner, Corrigan, Ditchman, & Sokol, 2012). Potential directions to further explore the nature of this type of discrimination might be found in justification theories whereby people believe that there are moral, ethical, legal, social, natural, and logical bases for their rejection (Biernat & Dovidio, 2000). For example, for members of the general public, stereotypes of incompetence and dependence might provide a cognitive justification and a clear conscience for the fact that people with intellectual disabilities have limited opportunities in competitive employment (Siperstein, Heyman, & Stokes, 2014; Siperstein, Parker, & Drascher, 2013); that there are many people with intellectual disabilities living in situations of poverty (Ditchman, Kosyluk, Lee, &

Jones, 2016); or that there are limited opportunities to be involved in choices that affect their own lives (Bekkema, de Veer, Wagemans, Hertogh, & Francke, 2015; Bekkema, de Veer, Wagemans, Hertogh, & Francke, 2014; Bowey, McGlaughlin, & Saul, 2005).

When future studies demonstrate stigma processes whereby justification beliefs are relevant within the general public, anti-stigma initiatives might especially aim to (1) address inequalities using elements of 'protest'. Within 'protest' interventions the injustice of stigma is stressed and a moral appeal is created for people to change their beliefs and behaviours. In the field of intellectual disabilities one study already demonstrated a 'protest' intervention to have stronger destigmatising effects than a 'contact' intervention in increasing empowerment beliefs and decreasing sheltering beliefs (Walker & Scior, 2013). Also in other fields, the importance of addressing injustice in the face of stigma has been demonstrated (Durrheim, Jacobs, & Dixon, 2014; Kay et al., 2007); (2) support self-advocates to continuously pose counter-examples of incompetence and dependence as to gradually modify the beliefs of the general public about people with intellectual disabilities (Rüsch, Angermeyer, & Corrigan, 2005; Walker & Scior, 2013). The general public's tendency to view people with intellectual disabilities as akin in being 'warm' and 'friendly' might in this respect work advantageously in the general public's willingness to attend to anti-stigma initiatives.

LIMITATIONS

The study has some important limitations. Even though the sample was stratified, it was a pilot study using a selective stratified convenience sample (n= 194) with some over- and underrepresentation of specific groups (e.g., people with higher education, and people familiar with people with intellectual disabilities). The sample was therefore not completely representative for the Dutch population and results should be interpreted with caution. To strengthen the evidence, future research might want to replicate the results within randomly selected population sample. Moreover, no definition of intellectual disabilities had been provided to participants. Even though this provided us with a response to the plain label 'intellectual disabilities', it might have been possible that participants would have related intellectual disabilities to other diagnoses/labels (e.g., Alzheimer's disease, mental illness).

People with intellectual disabilities continue to experience stark challenges when living within mainstream society (Scior et al., 2016). Stigma as an explanatory process concerning these challenges needs not to be underestimated and needs a continuing search for the nature of stigma and ways to combat it (Scior et al., 2016).

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Chapter 5

Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: a systematic review

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ABSTRACT

Background

Equal access to mainstream healthcare services for people with intellectual disabilities still requires attention. Although recent studies suggest that health professionals hold positive attitudes towards people with intellectual disabilities, stigmatising attitudes may influence their efforts to serve people with intellectual disabilities in community healthcare practice. To stimulate inclusion in mainstream healthcare services, this systematic review focussed on barriers in attitudes of mainstream health professionals towards people with intellectual disabilities.

Method

Five electronic databases were systematically searched and references in full text articles were checked for studies published in the English language between January 1994 and January 2016. A social–psychological triad of cognitive, affective and behavioural dimensions of stigmatising attitudes is used to structure and discuss the results.

Results

The literature search generated 2190 records with 30 studies that passed our exclusion criteria. Studies were mostly cross-sectional and of moderate quality. With respect to stigma, a lack of familiarity with and knowledge about people with intellectual disabilities was found. Intellectual disabilities were considered as a stable condition not under personal control. Moreover, mainstream health professionals had either low or high expectations of the capabilities of people with intellectual disabilities. Professionals reported stress, lack of confidence, fear and anxiety, a tendency to treat people with intellectual disabilities differently and a lack of supporting autonomy.

Conclusions

Stigmatising attitudes towards people with intellectual disabilities appeared to be present among mainstream health professionals. This might affect the ongoing challenges regarding inclusion in mainstream healthcare services. To facilitate inclusion in mainstream healthcare services, it is recommended to include contact and collaboration with experts- by-experience in education programs of health professionals. Future research should progress beyond descriptive accounts of stigma towards exploring relationships between cognitive, affective and behavioural dimensions as pointers for intervention. Finally, inclusion would benefit from an understanding of 'equal' treatment that means reasonable adjustments instead of undifferentiated treatment.

Current western policy stresses the importance of equal access to mainstream healthcare services for people with intellectual disabilities. Article 25 of the United Nations' Convention on the Rights of Persons with Disabilities specifies that persons with disabilities have 'the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability' (United Nations 2006). This implicates that persons with disabilities receive care of the same quality and the same range as provided to other persons. Preferably, care is provided as close as possible to one's own community and denial of health services should be prevented.

Health professionals are key persons in living up to the principle of inclusion in mainstream healthcare services and are, therefore, particularly mentioned in Article 25 of the convention. Health professionals should provide care of the same quality, *'including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care'* (Article 25d). However, attitudes of health professionals towards people with intellectual disabilities may influence their effort to support inclusion in mainstream healthcare services (Mansell et al. 2002; Cobigo & Stuart 2010).

Overall, positive attitudes towards providing mainstream healthcare towards people with intellectual disabilities have been reported (Gill et al. 2002; Melville et al. 2005). For example, primary care staff and hospital staff indicated that people with intellectual disabilities have the same rights for health services as other people (McIlfatrick et al. 2011). Next, professionals reported positive feelings about providing care for people with intellectual disabilities (Gill et al. 2002; Lewis & Stenfert-Kroese 2010; Wilkinson et al. 2013; Flynn et al. 2015) and, in one study, even perceived their contacts with people with intellectual disabilities as stimulating experiences (Slevin & Sines 1996). Despite these positive attitudes, the ideal of inclusion in mainstream healthcare services for people with intellectual disabilities is not considered as being sufficiently achieved (Krahn et al. 2006). Without negating the presence of positive attitudes among health professionals, (e.g. Gill et al. 2002; Melville et al. 2005), stigmatising attitudes that counteract inclusion in mainstream healthcare services might be present (Iacono et al. 2014). Preliminary evidence indeed affirms that stigmatising attitudes of mainstream health professionals can be a barrier for people with intellectual disabilities in the access to good quality, mainstream healthcare services (Lindsey 2002; Gill et al. 2002; Krahn et al. 2006). For example, studies describe the tendency of clinicians to overlook symptoms of mental health problems and attribute them to being part of 'having an intellectual disability' (diagnostic overshadowing) (Mason & Scior 2004; Werner et al. 2013). Also, people with intellectual disabilities and their carers have reported perceived discrimination and negative comments as a significant experience in general hospitals (Gibbs et al. 2008). It is thus crucial to examine the stigmatising attitudes of health professionals, and to create awareness to further improve inclusion in mainstream healthcare services.

The intellectual disabilities field, in contrast to the field of mental illness, however lacks a systematic conceptualisation of stigma (Ditchman et al. 2013). Stigma refers to the possession of a powerful label that conveys a devalued social identity within a certain context (Goffman 1963; Link & Phelan 2001). From a social– psychological perspective, stigmatising attitudes are related to cognitions, as well as to affective reactions and discriminatory behaviour (Dovidio et al. 2000; Link & Phelan 2001; Corrigan & Watson 2002). The cognitive dimension reflects the lack of knowledge and perceptions of, in this case, health professionals about people with intellectual disabilities (e.g. negative stereotypes, attributions). The affective dimension entails the emotional reactions of health professionals to people with intellectual disabilities (e.g. fear, pity). The behavioural dimension reflects the discriminatory behaviour or the behavioural intentions towards people with intellectual disabilities (e.g. social distance, discrimination) (Dovidio et al. 2000).

Stigmatising attitudes towards people with intellectual disabilities have received limited research attention and that only recently (Ditchman et al. 2013). This recent attention is apparent in stigma reviews concerning members of the general public (Scior 2011), medical students (Ryan & Scior 2014) and people with intellectual disabilities themselves (Ali et al. 2012). Research into the stigmatising attitudes of mainstream health professionals is also scarce. In the present review, we therefore aimed to appraise the findings of studies to address the following questions: (1) do mainstream health professionals hold stigmatising attitudes towards people with intellectual disabilities and (2) what is the nature of these attitudes? The social–psychological triad is used as a guideline to structure and discuss the results within the present review.

METHOD

Search strategy

The databases PubMed, Psych INFO, CINAHL and ProQuest (i.e. Social Services Abstracts and Sociological Abstracts) were systematically searched. These databases were chosen to include medical literature from both PubMed and CINAHL as well as psychological literature from Psych INFO. The ProQuest databases were included to cover all intellectual disabilities peer-reviewed journals. The aim was to discover studies evaluating stigmatising attitudes of mainstream health professionals towards people with intellectual disabilities. Studies were published in the English language in peer reviewed journals from January 1994 to January 2016.

Search terms were based on the PICO approach specifying Population, Intervention/ exposure, and Comparison and Outcome (Liberati et al. 2009) (see Table 1). In this study a comparison component was irrelevant because of the descriptive nature of the research question. Similarly, study designs were not specified because various empirical designs could provide relevant information regarding the research questions. Studies

could be either qualitative or quantitative in nature. Population was specified as health professionals with direct patient or client contact. Professionals with direct contact were defined as those professionals for whom treatment and/or care of patients/clients was an important part of their job description (e.g. nurses, GP's, dentists). Therefore, participants holding jobs like household staff, managers and directors, were excluded. Direct contact was assumed based on job titles and context information of the article. In case of uncertainty, the authors of an article were contacted to obtain this information. When articles included a mix of professionals with (e.g. nurses) and without (e.g. directors) direct patient or client contact, results were only included when: (1) separate results were provided for the different groups of professionals; or (2) it was demonstrated that there were no (statistically significant) differences between these groups. Furthermore, students were excluded because their stigmatising attitudes have been recently reviewed (Ryan & Scior 2014). Regarding the intervention/exposure, studies should concern people with intellectual disabilities. The outcome of research should include cognitive, affective or behavioural dimensions of stigmatising attitudes by which people are viewed or treated as devalued. Table 2 presents an overview of the inclusion and exclusion criteria.

Table 1 provides an overview of the search terms and strategy applied in PubMed using both Medical Subject Headings (MeSH) and additional text words. MeSH is the controlled vocabulary thesaurus that PubMed uses for indexing articles. Other databases have similar thesauri. The use of thesaurus terms did have two benefits. First, thesaurus terms enabled us to find articles about stigmatising attitudes independent of the words that articles used to describe stigma. Second, because of the hierarchical tree structure of thesaurus terms, it was possible to search for several specific terms under the heading of higher order terms. For example, by using the MeSH term 'health personnel', we automatically searched using approximately 100 specific terms (e.g. orthodontist, physical therapist). We repeatedly tested our search strategy to discover which text words were necessary in addition to thesaurus terms to find all relevant articles. The text words intellectual disab*, staff, service-provider* and attitude* were added to the search strategy. Similar search strategies were used in the other databases.

Study selection

The selection process for studies consisted of four phases: identification, screening, eligibility and inclusion (see Fig. 1). In the identification phase, records were identified in four different databases. The screening phase involved title and abstract selection, in which duplicates, essays and review studies were excluded. The titles were independently screened by two reviewers (HP and PE, WvO or JvW) based on the inclusion criteria. Records were retained when the title fulfilled all three inclusion criteria, or when there was uncertainty about the presence of a criterion. This strategy resulted in 84% agreement on average between the different reviewer-dyads. The reviewers discussed differences until full consensus was reached. Thereupon, the remaining records proceeded to the abstract selection where exclusion criteria were independently assessed by two reviewers

(HP and WvO) who achieved 77% agreement. Disagreements were again discussed until full consensus was reached. The other reviewers (PE and JvW) were consulted regarding complex decisions.

TABLE 1 | *Search strategy PubMed using Medical Subject Headings [MeSH] and text words.*

	PUBMED FINAL SEARCH STRATEGY
1	*Population: healthcare professionals*
#1	Health Personnel [MeSH]
#2	Staff [TI/AB]
#3	Service-provider* [TI/AB]
#4	**#1 OR #2 OR #3**
2	*Exposure: intellectual disability*
#5	Intellectual disability [MeSH]
#6	Mentally disabled person [MeSH]
#7	Developmental Disabilities [MeSH]
#8	Learning Disorders [MeSH]
#9	Intellectual Disab* [TI/AB]
#10	**#5 OR #6 OR #7 OR #8 OR #9**
3	*Outcomes: stigmatising attitudes*
#11	Social stigma [MeSH]
#12	Stereotyping [MeSH]
#13	Attitude [MeSH]
#14	Knowledge [MeSH]
#15	Social distance [MeSH]
#16	Social discrimination [MeSH: NoExp]
#17	Prejudice [MeSH: NoExp]
#18	Rejection [MeSH]
#19	Social Marginalization [MeSH]
#20	Attitude*[TI/AB]
#21	**#11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20**
4	*Outcomes & Exposure: stigmatising attitudes toward disability*[*]
	-
5	*Outcomes & Population: stigmatising attitudes of healthcare professionals*
#22	Attitude of Health Personnel [MeSH]
6	*Combining search term groups*
#23	**#4 AND #10 AND #21 (healthcare professionals & intellectual disability & stigmatising attitudes)**
#24	**#10 AND #22 (intellectual disability & stigmatising attitudes of healthcare professionals)**
#25	**#25 OR #26**

Note. TI/AB refers to the search for text words within title and abstract; MeSH refers to the search for Medical Subject Headings, the thesaurus terms that were used in PubMed. All thesaurus terms, unless stated otherwise, were expanded to various lower level terms. For example the term 'health personnel' encompassed all healthcare personnel from dentists to psychotherapist to nurses. Similar search strategies were used for Psych Info, ProQuest and CINAHL.[*] Not applicable within PubMed, but for example the thesaurus term 'attitude to disability' was used in CINAHL.

In the eligibility phase, full text articles were scrutinised for the presence of inclusion and exclusion criteria. These criteria were then extensively discussed by two reviewers (HP and WvO). In case of uncertainty about criteria, authors of the original article were contacted

for clarification. The quality of the remaining studies was assessed using the Multi Method Appraisal Tool (MMAT, Pluye et al. 2011), an instrument to assess the quality of studies with various research designs (i.e. qualitative, quantitative randomised, quantitative non-randomised, descriptive and mixed method studies). This instrument has demonstrated good content validity and reliability (Pluye et al. 2011). Appraisal was discussed by a senior researcher (WvO), experienced in conducting and supervising systematic reviews, and the first author (HP).

TABLE 2 | *Inclusion and exclusion criteria.*

Inclusion criteria
• Main participants of the study were mainstream healthcare professionals who have direct client or patient contact. Direct contact was defined as treatment-related contact (e.g., contact between nurses/therapists and patients).
• Outcome of the study comprised cognitive, affective or behavioural dimensions of stigmatising attitudes by which people are viewed or treated as devalued
• The study concerned people with ID
Exclusion criteria
Participants:
• Studies solely focusing on students
• Studies in which the sample included healthcare professionals without direct client contact (e.g. managers or directors) and/or no separate statistics for healthcare professionals with direct client contact were provided
• Studies about specialist ID staff[1]
Exposure:
• Studies focusing on disability in general
• Studies focusing exclusively on children with ID[2]
• Studies focusing on a specific subset of disability which was not necessarily related to ID (e.g., acquired brain injury; autism; epilepsy) and in which ID was not discussed
Outcome:
• Studies focusing on perception of training needs or need for support for staff
• Studies focusing on perception or attitudes toward a specific intervention, special care, or special services
• Studies focusing on sexual behaviour or challenging behaviour or bereavement without attention to attitude to people with ID themselves.
• Studies focusing on opinions about care for people with ID
• Studies focusing on attitudes toward specific prenatal screening tests
• Studies focusing on structural discrimination (e.g., structural barriers in accessing health care) without attention to stigmatising attitudes of healthcare professionals
General
• No original research
• Studies presenting merely psychometric data (i.e., validity and reliability of a measure)

Note. [1](1) we have used this criterion within the full text selection, (2) articles about specialist ID staff are separately archived for future research and (3) specialist ID staff was defined as health care professionals working for a specialist ID organisation. [2]Articles referring to 'people with ID' without specifying life-stage or age were included.

Quality criteria could be rated as 'present', 'absent' or 'can't tell'. In calculating scores, 'can't tell' evaluations were considered to be absent. Studies with a zero total score on the

screening questions or a zero total score on the four quality criteria were independently assessed by a third researcher with experience in conducting systematic reviews. If there was a consensus about the absence of positive scores, the study was removed from further analysis. Percentage scores of the quality appraisal are presented in Table 3. Finally, reference lists of the remaining articles were screened for potentially relevant studies. As a result, 15 additional full text articles were assessed for eligibility. Studies that were suitable based on the screening and eligibility phase were included in the present review.

Data extraction and analysis

Both general information and main results were extracted from the selected studies and summarised in Table 3. Because of the heterogeneity of the design, population, and setting of the included studies, a narrative synthesis rather than a structured analysis (e.g. meta-analysis) was most feasible.

RESULTS

Figure 1 depicts the selection process and includes the number of studies screened, assessed for eligibility, and included in the review. The databases search generated a total of 2190 records of which 30 studies were identified for final inclusion.

Background and research quality

With respect to background information, 10 studies were conducted in the United Kingdom, six in the United States, five in Australia, two in Ireland, two in the Netherlands and one each in New Zealand, India, Italy, Canada and Sweden. Professionals involved in the studies were dentistry-related practitioners *(n* = 4), general practitioners (GPs; *n* = 9), nurses (*n* = 5), practitioners working in psychiatry (*n* = 4), midwives (n = 1), rehabilitation service providers (*n* = 1), community service workers (*n* = 1) or a mix of different practitioners (*n* = 4).

Included studies used various designs and were of diverse quality. Twenty-five studies used a quantitative approach, four studies were qualitative and one study used a mixed methods design. Generally, studies were of moderate quality as assessed using the MMAT. Quality assessment found two studies of lower than acceptable quality which were therefore removed from further analyses. The main methodological limitation of the remaining quantitative studies concerned the sampling. Mostly convenience samples from a medical association or congress were used. Studies, however, that sampled widely in a certain area or large database generally obtained a small response rate. In descriptive studies, measures with unclear origin were often used. Methodological limitations of qualitative studies mainly concerned the limited attention towards reflexivity on how findings relate to the researchers' influence (e.g. researchers perspective, role and interaction with participant), and a limited description of the context of the study and its influence on the results.

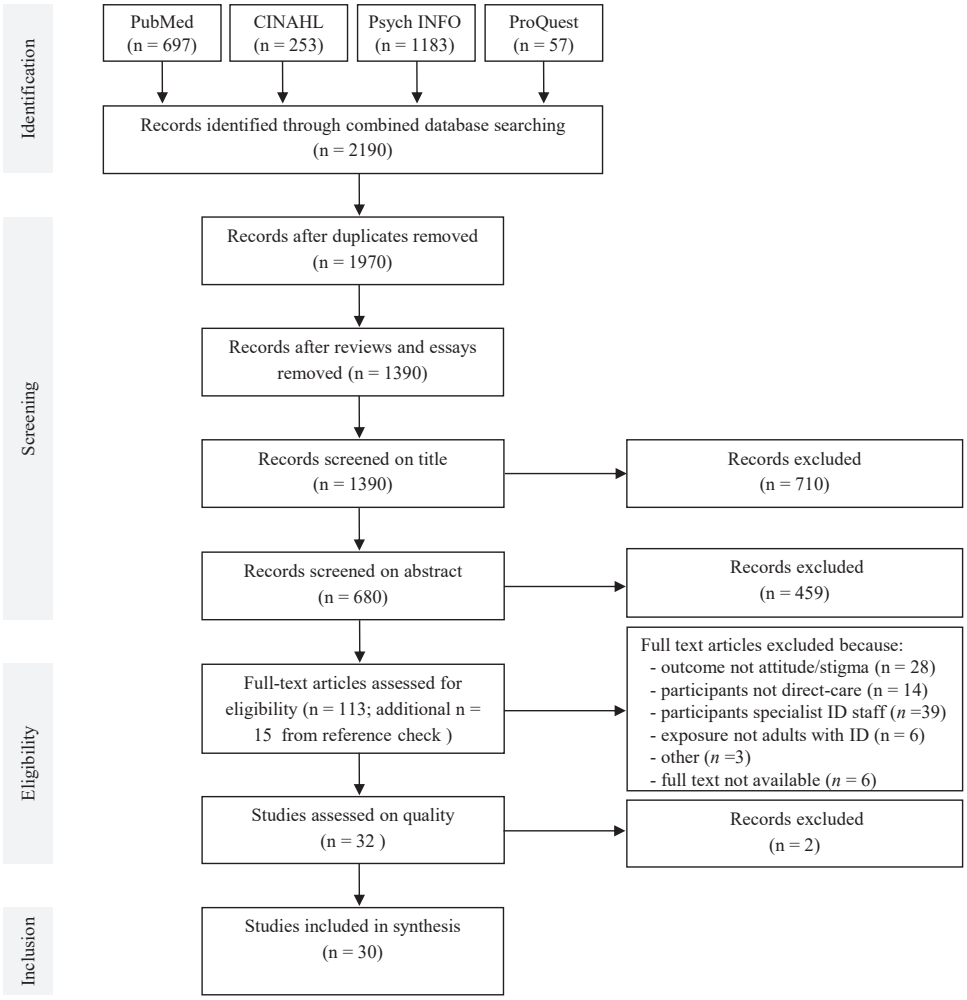

FIGURE 1 | Flowchart of the literature selection process.

The content of the studies will be discussed following the triad of cognitive, affective and behavioural dimensions of stigma. Because of the focus on barriers in attitudes, positive attitudes have not been reported.

TABLE 3 | *Main characteristics of the studies included and summary of relevant results.*

#	Authors	Country	Design	Setting	Participants
1	Bedi *et al.* 2001	UK	1	General post-graduate dental course	General Dental Practitioners (GDP's) (*n*=74) Professionals complementary to dentistry (PCD's) (*n*=89)
2	Bekkema *et al.* 2014	NL	1	National registration of GPs; research panel of registered ID care staff; Dutch professional association of ID physicians.	GPs (*n* = 377) ID physicians (*n* = 145) Care staff (*n* = 196)
3	Bekkema *et al.* 2015	NL	1	National registration of GPs; research panel of registered ID care staff; Dutch professional association of ID physicians.	GPs (*n* = 377) ID physicians (*n* = 145) Care staff (*n* = 196)
4	Brown & Inglehart 2009	US	1	Active members of the American Association of Orthodontists and orthodontic residents	Orthodontic residents (*n* = 135) Orthodontists (*n* = 568)
5	Brown & Inglehart 2011	US	1	Orthodontic residents and active members of the American Association of Orthodontists	Orthodontic residents (*n* = 135) Orthodontists (*n* = 568)
6	Dovey & Webb 2000	NZ	2	Registered GP's in the southern region of New Zealand	GP (*n* = 137)
7	Edwards *et al.* 2007	AU	2	Royal Australian and New Zealand Council of Psychiatrists residing in Queensland	Psychiatrists (*n* = 306) Psychiatric registrars (*n* = 104)
8	Flynn *et al.* 2015	UK	1	UK Oncology Nursing Society	Nurses working in oncology or related field (i.e. palliative care) (*n* = 83)
9	Gill *et al.* 2002	UK	1	Practicing GPs registered within three health authorities	GP *(n*=226)

Outcome Instrument	Stigmatising attitudes – results	Quality Appraisal*
Attitude scale about discriminatory views towards dental care for patients with ID	DP's were concerned with treatment effectiveness, stress related to treatment, and whether people with ID should be treated in general practice.	(2/4) 50%
Questionnaire about 1- case-related considerations about end-of-life care 2- beliefs about medical interventions	GGPs score lower than care staff & similar to ID physicians on statement 'client wishes about whether to use medical interventions should always be leading' GPs score lower than care staff on the item 'if a clients' wishes are not in line with the opinion of the caregivers, the clients' wishes prevail.'	(2/4) 50%
Questionnaire about 1- place of end-of-life care for recent patient with ID 2- beliefs about appropriate environment for end-of-life care	GPs score lower than care staff on the item: 'the clients' wishes as to where they want to live at the end of life should always be leading'	(2/4) 50%
Questionnaire about 1- educational experiences 2- attitudes concerning treatment 3- provision of care	41.4% of orthodontists disagreed with item: I like to treat patients with mental retardation, 38.1% was neutral, 20.6 % agreed. 23.6% of orthodontists disagreed with the item: 'I am confident treating patients with mental retardation; 25.9% is neutral, 48% agrees.	(1/4) 25%
Questionnaire about 1-educational experiences 2- attitudes concerning treatment 3- behavioural intentions	The more positive attitudes the more likely to treat patients with ID. White respondents more likely to treat people with ID than non-European respondents.	(1/4) 25%
Questionnaire about 1- behavioural medication 2- specialist support 3- organisation of care 4- rural/urban trends 5- open question	7.3% GPs disagrees they are responsible for medical care of people with ID in community; 30.7% is neutral, 62% agrees. 49.6% of GP's disagrees that all people with an ID should live in the community, 32.8% is neutral, and 15.3% agrees. Open comments: some people are better cared for in an institution; community living depends on severity and family support available.	(3/4) 75%
Questionnaire about 1- management of adults with ID 2- training needs	58% agrees they prefer not to treat people with ID; 34% disagrees. 9	(1/4) 25%
1- Care perceptions and attitudes scale 2- Perceived stress scale	Caring for people with ID compared to other patients perceived as more difficult. In reaction to vignettes less comfortable talking to people with ID about their illness; less positively about providing care for them. Caring for people with ID would more easily cause stress. Medium to large effect sizes found. Previous experience with people with ID related to positive attitudes.	(2/4) 50%
1- Attitude scale 2- Emotional experience scale	Behavioural intentions (e.g. adapting communication, or allowing more time) lower than general beliefs (e.g. working with people with ID is part of GP's role). Negative and positive attitudes within open questions.	(2/4) 50%

#	Authors	Country	Design	Setting	Participants
10	Gilmore & Malcolm 2014	Au	1	Practicing GPs in the state of Queensland	GP (*n* = 106)
11	Höglund *et al.* 2013	Se	1	Antenatal care and labour wards in Sweden	Midwives (*n* = 375)
12	Lennox & Chaplin 1995	Au	2	Public psychiatric services in Victoria	Psychiatric trainees and medical officers (*n*= 116)
13	Lennox *et al.* 1997	Au	2	Full- and part-time medical practitioners acknowledged and registered as GP in Australia	GPs (*n* = 526)
14	Lewis & Stenfert-Kroese 2010	UK	1	General medical and surgical wards from six general hospitals	Nursing staff (*n*= 268)
15	McConkey & Truesdale 2000	Ire	1	1- Hospital & community; 2- Occupational/ physio therapists; 3- ID day/residential care; 4- University courses	1- Post-qualified nurse (*n*=269) 2- Therapist (*n*=169) 3- ID Staff (*n*=270) 4- Undergraduate student (*n*=261)
16	McIlfatrick *et al.* 2011	UK	3	Three Health & Social Care Trusts across Northern Ireland; primary care group for a local cancer network	1- Primary care staff (e.g. GPs and practice nurses) (*n*= 9) 2- Breast screening staff (*n*= 9)
17	Melville *et al.* 2005	UK	2	Healthcare practices for health promotion, health monitoring and disease-specific clinics	Practice nurses (*n*= 201)

	Outcome Instrument	Stigmatising attitudes – results	Quality Appraisal*
	1- ASQ- General Population 2- ASQ- ID	Less support for sexual freedom of adults with than without ID. Views positive for sexual rights, non-reproductive sexual behaviour, self-control, less positive about parenting. For men with ID 23%, for women with ID 41% of the GPs endorsed sterilisation as desirable practice. Attitudes to male and female sexuality similar. Older GP's more support for sterilisation. Majority believe sterilisation desirable in nine conditions e.g., when individual is unable to parent, or when available parenting support is limited or costly.	(2/4) 50%
	Questionnaire about 1- Knowledge 2- Attitudes 3- Experiences 4- Education (needs)	Only 1/3 of midwives had good knowledge about women with ID. 1/3 felt women with ID should not be pregnant and become mothers; 2/3 agreed they cannot manage the mother role satisfactorily. Midwives felt uncertainty how to adapt advice to people with ID (85%); find it difficult to give advice (80.1%). Most agreed that children of people with ID should grow up with parents and accompanying support. 1/5 agreed children should grow up in foster care. More professional years and experience with ID related to more knowledge.	(3/4) 75%
	Questionnaire about people with ID seen; opinions management; improvement of services; interest ID	1/3 of psychiatrist prefer not to treat people with dual disabilities 9	(2/4) 50%
	Questionnaire about 1- work environment 2- level of training 3- willingness for education 4- personal experiences 5- barriers in providing care	6Last six months 60% saw between 0-5 persons with ID. 15% of GPs would personally prefer not to treat people with ID. 38% of GPs disagree that they felt confident treating people with ID. 80% agrees it is harder to provide good quality healthcare. Many GPs reported lack of knowledge about conditions common in people with ID.	(3/4) 75%
	Questionnaire on 1- Attitudes 2- Positive emotions 3- Negative emotions	Less positive attitudes, fewer positive emotions, more negative emotions towards people with ID than physical disabilities.	(2/4) 50%
	Questionnaire on 1- Previous contact 2- Confidence at meeting 3- Willingness for social contact	Therapists and nurses more confident meeting people with physical disabilities than ID.	(1/4) 25%
	Focus group and telephone interviews 1- knowledge of risk factors 2- experience supporting women with ID in breast cancer screening 3- barriers and solutions	Participants reported low cognitive functioning as main risk factor associated with breast cancer; this risk factor related to low expectations of capabilities of people with ID e.g., lack of ability to self-examine, poor literacy skills to understand the invitation for screening, and poor attendance for screening.	(2/4) 50%
	Questionnaire about knowledge, attitudes, self-efficacy and training needs	9Practice nurses feel they have an important role in meeting health needs of people with ID (75.2% agree); although ID nurses should have the main role in meeting nursing needs according to 43.7%. 1.5% considers people with ID to be of low priority compared to other patients.	(2/4) 50%

#	Authors	Country	Design	Setting	Participants
18	Mesa & Tsakanikos 2014	UK	1	Qualified staff from an acute inpatient psychiatric ward	Staff (i.e., nurses, occupational therapists, psychiatrists, social workers) (*n* = 68)
19	Nagarajappa *et al.* 2013	In	1	Private practitioners at 60 dental clinics, faculty & postgraduate students of dental institutions	Dentists (*n*=247)
20	Ouellette-Kuntz *et al.* 2003	Ca	1	Preparatory session for the certification examination of the Royal College of Physicians and Surgeons	Senior psychiatry residents (*n*= 58)
21	Pace *et al.* 2011	US	1	Opt-in verified panel of 135.000 medical practitioners	1- Paediatricians (*n= 250)* 2- Obstetricians/gynaecologist (*n*=250) 3- Internist (*n* = 490) 4- Family practitioner (*n* = 510)
22	Shankland & Dagnan 2015	UK	1	National Health Service Trusts in North West England	IAPT therapists (*n* = 55)
23	Slevin & Sines 1996	Ire	4(3)	General hospital setting	Graduate/Non-graduate nurses (*n*=10)
		Ire	4(1)	General hospital setting	Graduate/Non-graduate nurses (*n*= 31)
24	Sowney & Barr 2006	UK	3	Accident and emergency departments in general hospitals	Nurses (*n* = 27)

Outcome Instrument	Stigmatising attitudes – results	Quality Appraisal*
1-CLAS 2- Self-efficacy scale	70.6% of psychiatric staff agreed that people with mild ID should be admitted to general psychiatric inpatient care. Psychiatric staff demonstrated no differences in attitudes of similarity, sheltering and exclusion between mental illness and ID; scores for empowerment were higher in MI than ID group.	(1/4) 25%
Questionnaire about 1- Experience 2- Attitudes (beliefs, capabilities, discrimination, social behaviour, quality of care)	61% of dentists say treating people with ID causes too much stress. Dentists doubted capabilities, e.g. people with ID can reach same standard of oral hygiene as other people (78% disagrees); able to make own healthcare decisions (22.8% agrees). Social behaviour may be disturbing.	(3/4) 75%
1- Exposure-scale 2- CLAS (short form)	Sheltering scores neutral. Residents feel people with ID should somewhat we protected.	(2/4) 50%
5 questions about inclusion of people with Down Syndrome (DS)	24.2% agreed that including students with DS in classes with typically developing students is distracting, 36.7% responded neutral, and 39% disagreed. 9.8% uncomfortable providing medical care to a person with DS, 14.3% neutral, 76% comfortable.	(1/4) 25%
Questionnaire on attitudes, confidence, self-efficacy towards working with people with ID; open questions about opinion towards providing therapy to people with ID	16% agrees therapy could not be offered in mainstream services; themes mentioned by participants: therapists should adapt, even if more difficult (62.5%); difficult to treat people with ID without extra training (100%); not possible for severe impairment (35.7%); people with ID less ability to make changes based on therapy (70%); rigidity of thinking (30%). Therapists have lack of confidence (33%) and knowledge (25%) in treating people with ID. Several patient-based limitations mentioned.	(1/4) 25%
Semi-structured interviews about knowledge, perceived differences, need for ID carer, perceived fears, location in ward, contacts with people with ID, communication, perceived education need.	Cognitive: labelling of ID as low intelligence (30%) or as Down syndrome/altered brain structure, not social impairment; 31% people with ID totally different, having poor expectations, expecting bizarre behaviour; Affective: 47% fear related to violence; 35% felt awkward, not able to cope or frightened about contacts experiences; 50% felt not competent communicating 28% felt competent; behavioural: 31% people with ID in side room due to their behaviour; 60% no social contacts with people with ID.	(7/11) 64%
ATDP	No general mean scores provided.	
Focus groups on previous opportunities to work with people with ID; previous experiences in the A & E with people with ID; challenges; views on what helped them to provide care	Fear and vulnerability because of: not knowing how to respond, embarrassment if you don't know how to react'; not knowing about ID; diagnostic overshadowing or over-investigation; missing out serious problem; treating them differently. Lack of knowledge about ID related to fear. Misunderstanding that carers could consent for adult with ID for examination treatment and care: reduces right to assert control over own bodies and make decisions about examination care and treatment.	(1/4) 25%

#	Authors	Country	Design	Setting	Participants
25	Stein 2000	UK	2	64 Practices of GPs in a district	GPs (*n*= 48)
26	Strauser *et al.* 2009	US	1	Community based rehabilitation	Rehabilitation service providers (*n*= 98)
27	Tartakovsky *et al.* 2013	Il	1	NGO community services for people with ID and people with severe mental illness (SMI)	1- Community service workers in ID (*n*=126) 2- Community service workers in SMI (*n*= 96)
28	Torr *et al.* 2008	Au	1	Fellows of Victorian branch of Royal Australian and New Zealand College of Psychiatrists	Psychiatrists (*n* = 170)
29	Wilkinson *et al.* 2012	US	3	Academic practice, private practice, ID-focused practice; national e-mail list and conference attendees list	GPs (*n* = 22)
30	Wilkinson *et al.* 2013	US	3	Community-based organisations; local practices and national email list.	Women with ID > 40 years of age (*n* = 27) GP (*n* = 22)

Note. Study design: 1 = cross sectional; 2 = descriptive; 3 = qualitative; 4 = mixed method. Questionnaires: Community Living Attitude Scale (CLAS); Attitudes to Sexuality Questionnaire (ASQ); Attitude Towards Disabled Persons scale (ATDP). More results are presented within articles, however only results which were relevant and dealt with direct-care professionals were subtracted from the article. *Quality scores are based on information available within the article when answering the MMAT questions.

Outcome Instrument	Stigmatising attitudes – results	Quality Appraisal*
Questionnaire about 1- Demands of people with ID 2- Confidence & training needs; 3- Provision of services; 4- Attitudes to screening	Majority of GPs willing to meet primary care needs in general medical services yet need time, funds & cooperation with ID service. All aspects of care for people with ID should be met by professionals working with ID services, (29.7% agree; 21.3% undecided; 48.9% disagree); GPs should meet the primary healthcare needs of people with ID as part of general medical services. (62.2% agree; 10.6% undecided; 27.7% disagree).	(3/4) 75%
Psychiatric Disabilities Attribution Questionnaire	Stability: ID scored above the threshold on the subscale of stability indicating a stigmatising view that people are not likely to benefit from treatment or are likely to recover. Controllability: For controllability people with ID scored lowest compared to other disabilities indicating that people with ID are not held responsible for their condition.	(1/4) 25%
1- CLAS 2- Value preference-scale 3- Burn out-scale	High scores on value of power were related to lower levels of empowerment and similarity and higher levels of exclusion. Self-direction and similarity positively related; benevolence and similarity positively related.	(3/4) 75%
Questionnaire about people with ID seen; opinions management; improvement of services; interest ID	I would prefer not to treat people with ID: neutral mean scores and a higher score in 2004 compared to 1994. Individual supportive psychotherapy can be a useful intervention, high mean score. Inpatient psychiatric care should be provided in units dedicated to adults with ID, mean score indicates moderate agreement.	(1/4) 25%
Experience caring for people with ID and needed resources; previous experience; medical training; recommendations	GPs felt unfamiliarity with daily lives of people with ID. Discomfort & lack of confidence when interacting with people with ID: main issue leading to frustration. Sometimes stereotyping as beautiful people, not being locked up. Feeling overwhelmed and out of control about interactions with people with ID. Not knowing what to expect from patients with ID, perceived as different and somewhat intimidating. Sometimes anxiety about challenging behaviours.	(2/4) 50%
Experience with ID; resources needed; previous life experience with ID and training needs	Physicians felt frustration at time needed to see patients with ID; time = luxury; and felt regret and guilt about not spending as much time as necessary to provide high quality care. Physicians expressed positive feelings about relationship with people with ID. Positive feelings related to being perceived positively by others because of working with this potentially challenging population. A-feel-good population. Physicians trying to say something nice about patients with ID but comments indicated seeing people with ID as children (like kids, simple), or people who following commands.	(1/4) 25%

Cognitive dimension

Knowledge and familiarity

A lack of knowledge about and familiarity with intellectual disabilities was found. Most nurses reported little knowledge of the nature of intellectual disabilities and associated healthcare issues (Sowney & Barr 2006). Only one third of midwives had good knowledge about women with intellectual disabilities (Höglund et al. 2013), and GPs commonly mentioned a lack of knowledge about conditions common in people with intellectual disabilities (Lennox et al. 1997). Moreover, GPs felt unfamiliar with the daily lives of people with intellectual disabilities (Wilkinson et al. 2012). Also, McConkey and Truesdale (2000) reported that up to a quarter of nurses and therapists in their study have had no contact at all with people with intellectual disabilities. A third of the GPs did not know anyone with intellectual disabilities outside their practice, and almost two thirds had seen between zero and five patients with intellectual disabilities during the previous six months (Lennox et al. 1997). Lack of familiarity is especially important because several studies found that previous contact with people with intellectual disabilities is associated with less stigmatising attitudes (Slevin & Sines 1996; McConkey & Truesdale 2000; Bedi et al. 2001; Gill et al. 2002; Ouellette-Kuntz et al. 2003; Höglund et al. 2013; Nagarajappa et al. 2013; Flynn et al. 2015).

Attributions of stability and controllability

Attributions of intellectual disabilities differ from the attributions of other medical conditions. Rehabilitation service providers perceived intellectual disabilities as the most stable condition not under personal control when compared to depression, cocaine addiction, cancer, AIDS or psychosis. That is, people with intellectual disabilities were not held responsible for their condition and were also not likely to benefit from treatment or to recover (Strauser et al. 2009). Additionally, many psychotherapists doubted the ability of people with intellectual disabilities to make changes in their lives based on psychological treatment (Shankland & Dagnan 2015).

Expected capabilities

Although dental auxiliaries in the UK and physicians in the USA demonstrated high expectations of the capabilities of people with intellectual disabilities (Bedi et al. 2001; Pace et al. 2011), opposite attitudes were also reported. For example, over three quarters of dentists in India doubted the capabilities of people with intellectual disabilities to maintain oral hygiene, make healthcare decisions or understand the explanation of their treatment plan (Nagarajappa et al. 2013). Breast cancer screening staff reported low expectations as well, for example about people's understanding and awareness of breast care, the ability to self-examine and attendance for screening (McIlfatrick et al. 2011). Moreover, in the study of Höglund et al. (2013), two third of the midwives thought that mothers with intellectual disabilities could not manage the mother-role satisfactorily.

Stereotypical perceptions

Most nurses viewed people with intellectual disabilities as more difficult to care for than people with physical disabilities because they would less easily comply with requests, would be more easily distressed, would be more emotional, possibly aggressive and less cooperative (Lewis & Stenfert-Kroese 2010). Similarly, GPs in a qualitative study by Wilkinson et al. (2012) perceived people with intellectual disabilities as different and somewhat intimidating. Some physicians in a qualitative study referred to people with intellectual disabilities as 'children or people who follow commands', and also as 'pleasant, delightful and funny people' (Wilkinson et al. 2013). Two studies reported that health professionals expected strange or intimidating behaviour from people with intellectual disabilities. A third of the interviewed nurses referred to people with intellectual disabilities as being totally different and demonstrating bizarre behaviour (Slevin & Sines 1996).

Affective dimension

Feelings of stress and confidence

Mainstream health professionals reported stress and a lack of confidence in providing care for people with intellectual disabilities. Health professionals were less confident and more stressed in relation to patients with intellectual disabilities than patients without intellectual disabilities or with physical disabilities (McConkey & Truesdale 2000; Lewis & Stenfert- Kroese 2010; Flynn et al. 2015). About half of the orthodontists and a third of GPs did not feel confident in treating people with intellectual disabilities (Brown & Inglehart 2009; Lennox et al. 1997). In a study of Nagarajappa et al. (2013), two thirds of participating dentists reported that caring for people with intellectual disabilities would cause them to be stressed. GPs reported this lack of confidence to be a main issue leading to frustration when working with people with intellectual disabilities (Wilkinson et al. 2012).

Feelings of fear and anxiety

Fear and anxiety were reported among professionals. Two studies reported that half of the nurses and some GPs feared the possibility of challenging behaviour (Slevin & Sines 1996; Wilkinson et al. 2012) and not knowing what to expect from people with intellectual disabilities (Wilkinson et al. 2012). In addition, several nurses reported a fear of missing a serious problem because of diagnostic overshadowing, a fear of treating people with intellectual disabilities differently and some reported a fear of embarrassment if they did not know how to react (Sowney & Barr 2006).

Behavioural dimension

Supporting autonomy

Several studies indicated insufficient support of autonomy and decision making of people with intellectual disabilities. Mainstream health professionals focussed on the carer

accompanying people with intellectual disabilities to gain information because it was seen as more efficient (e.g. Gill et al. 2002; Sowney & Barr 2006; Nagarajappa et al. 2013). Furthermore, GPs had lower scores than specialist intellectual disabilities staff on items relating to whether the wishes of clients should be paramount in decisions about medical interventions or residency (Bekkema et al. 2014; Bekkema et al. 2015). Also, Sowney and Barr (2006) reported that, for accident and emergency unit nurses, there was a common but misguided assumption that carers could consent to treatment and care on behalf of an adult with intellectual disabilities. Finally, the support of empowerment by psychiatric staff was found to be lower for people with intellectual disabilities than for people with a mental illness (Mesa & Tsakanikos 2014). Psychiatric staff believed that, to some extent, people with intellectual disabilities must be protected (Ouellette-Kuntz et al. 2003).

Treating differently

Results indicate that professionals sometimes have the tendency to treat patients with intellectual disabilities differently compared to patients without intellectual disabilities. A third of the nurses interviewed in a general hospital would for example place people with intellectual disabilities on a side ward so as not to disturb other patients (Slevin & Sines 1996). In a comparable study, nurses indicated that they were on average more willing to place people with intellectual disabilities on a side ward than people with physical disabilities. The same group of nurses would also avoid invasive interventions more easily with people with intellectual disabilities than people with physical disabilities because they would be more difficult to carry out (Lewis & Stenfert- Kroese 2010).

Providing access to mainstream healthcare services

Most health professionals agreed with the right of people with intellectual disabilities to be treated in mainstream healthcare practice (e.g. Stein 2000; Melville et al. 2005); stigmatising attitudes were found for a minority of health professionals. Sometimes, health professionals were negative because people with intellectual disabilities were seen as a burden on their time and that their cases were complex (Stein 2000; Wilkinson et al. 2013). Three similar studies indicated that 58% of psychiatrists, 33% of psychiatrists and 15% of GPs would personally prefer not to treat people with intellectual disabilities (Lennox & Chaplin 1995; Lennox et al. 1997; Edwards et al. 2007). Almost half of GPs agreed that not all people with intellectual disabilities should live within the community and indicated that some people are better cared for in institutions dependent on the severity of ID and the level of family support available (Dovey & Webb 2000). Finally, GPs achieved higher ratings to general beliefs (e.g. GP's responsibility for the primary care of people with intellectual disabilities) and lower ratings to items regarding the willingness to adjust their care practice to people with intellectual disabilities (e.g. adapting communication or allowing patients with intellectual disabilities to use more time) (Gill et al. 2002).

DISCUSSION

To facilitate future improvement of inclusion of people with intellectual disabilities in mainstream healthcare services, this systematic review focussed on stigmatising attitudes of professionals working in these services. Despite existing positive attitudes, the ideal of equal inclusion is not considered as being sufficiently achieved. Therefore, we questioned whether mainstream health professionals hold attitudes that stigmatise people with intellectual disabilities and what the nature of these attitudes is. The 30 studies included in this review were mainly cross- sectional self-report studies of moderate quality and conducted in Western countries. Results were structured following the social–psychological triad of cognitive, affective and behavioural dimensions of stigmatising attitudes.

Methodologically, the interpretation and generalisation of the results might be affected by the quality of the studies that were included in this review. In quantitative studies, samples were mostly selective or, measures with unclear origin were used. Few studies had a clear theoretical foundation or a systematic approach using conceptual models. In qualitative studies, insufficient attention was paid to reflexivity regarding the influence of researchers and contexts on the results. This limited the reliability of the results. Other reviews of stigmatising attitudes have reported similar problems with the quality of primary studies (Werner & Stawski 2012; Ryan & Scior 2014). The use of direct self-report measures may have provoked socially desirable answers to questions. Indirect measures of stigmatising attitudes may elicit less positive attitudes from health professionals (Werner 2015). Moreover, primary studies were mainly conducted in western countries and, therefore, lacked cultural diversity. This is relevant because it has been shown that cultural differences exist in stigmatising attitudes towards intellectual disabilities (Scior et al. 2013). The present review itself has also some limitations. Because we aimed to focus on stigmatising attitudes of mainstream health professionals, outcomes are not useful for proportional comparisons between positive and stigmatising attitudes. Next, the search was limited to only articles written in English, thereby excluding possible relevant articles in other languages. Our search strategy could have been improved by making more extensive use of text words alongside thesaurus terms. Finally, no structured analysis of the results could be conducted because of the variety of research methodologies, content subjects and samples within the primary studies. Despite general agreement that people with intellectual disabilities have the right to be included in mainstream healthcare practice, and despite the willingness of mainstream health professionals to increase their knowledge about people with intellectual disabilities (e.g. Melville et al. 2005; Flynn et al. 2015), the actual attitudes of health professionals seem to be rather complex (e.g. Gill et al. 2002). Present results showed that stigmatising attitudes towards people with intellectual disabilities are found among professionals. A lack of familiarity with and knowledge about people with intellectual disabilities was found. Moreover, people with intellectual

disabilities were perceived as different compared to other patients and as well as childlike, funny, strange or intimidating. Professionals reported low or high expectations of the capabilities of people with intellectual disabilities. They also reported stress, lack of confidence, fear and anxiety in caring for people with intellectual disabilities. A tendency to treat people with intellectual disabilities differently from other patients and a lack of addressing autonomy of people with intellectual disabilities was reported. In addition, professionals were ambiguous in their willingness to change and adapt their daily care practices to people with intellectual disabilities.

One explanation for the complex nature of attitudes might be related to professionals' experiences of complex ethical dilemmas. They are challenged to maintain a delicate balance between avoiding stigmatisation of and favouring equal rights for people with intellectual disabilities on the one hand, and protecting them from exploitation and harm on the other (Jenkins & Davies 2011). Therefore, stigmatising attitudes that were reported in this review may sometimes reveal actual dilemmas in care practice. For example, genuine concerns were expressed about whether the highest quality of healthcare for people with intellectual disabilities could be provided in community settings or not (e.g. Bedi et al. 2001).

When integrating the results of this review, three findings with clear implications for improving inclusion of people with intellectual disabilities in mainstream healthcare services can be described. First, anti-stigma interventions for mainstream health professionals should include both education and contact as key components. Educational interventions may improve the self-efficacy of health professionals to provide healthcare to people with intellectual disabilities (Bandura 1977; Dagnan et al. 2015; Hemm et al. 2015). Several studies demonstrated a perceived lack of knowledge in professionals, ranging from knowledge about the nature of intellectual disabilities to common health needs in this population. Education has been proposed to increase the confidence of professionals in treating people with mental illness (Henderson et al. 2014), and similar might be expected for the treatment of people with intellectual disabilities. In addition to education, interpersonal contact is known to be efficient in reducing prejudice between majority and minority groups (Pettigrew 1998). For example, within psychiatry contact has demonstrated consistent results in counteracting stigmatising attitudes (Corrigan et al. 2002) with even filmed social contact being effective (Clement et al. 2012). Comparably, contact and collaboration with experts-by-experience with intellectual disabilities seemed to improve medical students' attitudes as well as health researchers' awareness of the needs of people with intellectual disabilities (Ryan & Scior 2014; Frankena et al. 2015). Prerequisites for contact being effective in counteracting stigmatising attitudes have frequently been studied: the contact should be positive, non- hierarchical and in a context focused on cooperation (Pettigrew 1998). The frequency and quality of contact should also be taken into account (Morin et al. 2013). These factors of contact may be well represented within a humanistic approach to healthcare (Embregts 2011). A second implication is that

future studies should progress beyond descriptive accounts of stigma towards exploring the relationship between cognitive, affective and behavioural dimensions of stigma (e.g. Gill et al. 2002). Studies should attempt to unravel the processes involved in stigma that can negatively affect people with intellectual disabilities and their social inclusion (Ditchman et al. 2013). These relationships could be pointers for interventions, for example to reduce segregation (i.e. behaviour), a focus on preceding fears (i.e. affect) or perceptions of the dangers that people with intellectual disabilities pose (i.e. cognition) is needed (Corrigan et al. 2002). Qualitative studies may provide hypotheses for relationships because these studies aim to describe the processes of a phenomenon rather than the prevalence. For example, Sowney and Barr (2006) indicated that professionals' lack of confidence (i.e. affect) in working with people with intellectual disabilities was related to a lack of knowledge (i.e. cognition). Finally, although many health professionals support the equal right of people with intellectual disabilities to be treated in mainstream healthcare services (e.g. Stein 2000; Melville et al. 2005), stigmatising attitudes towards people with intellectual disabilities were also found. The finding that nurses feared that they would treat people with intellectual disabilities differently as well as the finding that GPs were ambiguous about adjusting healthcare practice seem to be characteristic in this context (Gill et al. 2002; Sowney & Barr 2006). These findings advocate the assumption that social inclusion of people with intellectual disabilities would benefit from an understanding that 'equal' treatment means reasonable adjustments instead of undifferentiated treatment. This understanding is often lacking among mainstream health professionals (Tuffrey-Wijne et al. 2014). Thus, discussion about a social justice framework might be needed where additional resources for people with intellectual disabilities are justified to reach a similar capability (e.g. Reindal 2009).

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Chapter 6

Stigma research in the field of intellectual disabilities:
A scoping review on the perspective of care providers

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ABSTRACT

Objectives

Care providers are key agents in the lives of individuals with an intellectual disability. The quality of their support can be affected by manifestations of stigma. This scoping review was conducted to explore studies that provide indications of care providers' stigmatisation of people with intellectual disabilities.

Methods

A structured search was made in four databases to identify relevant studies in English-language peer-reviewed journals. Records were systematically and independently screened by the researchers.

Results

The 40 articles included in this review were mainly conducted in Western countries and used Likert- type self-report measures of explicit attitudes. Stigmatisation seemed more distinct concerning people with high support needs. The few studies on public stigma preliminary suggest that staff may also stigmatise people with intellectual disabilities based on other social identities. Regarding the support of structural stigma, staff reported scepticism regarding community inclusion for people with high support needs, and tended to be ambivalent about the protection-or-empowerment balance in the support of people with intellectual disabilities. Possible indications of stigmatisation regarding sexuality were found on specific issues, such as self-determination and privacy. Agreement of staff with certain rights did not necessarily lead to staff acting in accordance with such rights.

Conclusion

Indications of stigmatisation of people with intellectual disabilities by care providers were found. Stigmatising attitudes might affect the quality of care providers' support. Potential leads for future interventions concern creating awareness, sharing power, addressing diagnostic overshadowing, and providing explicit policy translations. Directions for future research concern strengthening the methodology of studies and enriching the studied topics.

Most people with intellectual disabilities need life-long support in one or more areas of life (e.g. Wehmeyer et al. 2012). This support is, for a significant part, provided by care providers (e.g. support staff) (Sanderson et al. 2017) who fulfil a broad range of needs in the lives of people with intellectual disabilities. For example, care providers are a source of emotional and practical support (Giesbers et al. 2019, Van Asselt-Goverts et al. 2013), can increase possibilities for choice and independence (Channon 2014, Felce 1998), manage situations of social participation and social roles (Bigby and Wiesel 2015, Todd 2000), and expand and strengthen social networks of people with intellectual disabilities (Van Asselt-Goverts et al. 2014). Thus, care providers are key agents in the lives of individuals with intellectual disabilities and the quality of the support they provide is important (Giesbers et al. 2019).

Studies in related care fields have demonstrated that the quality of care provider's support can be affected by their stigmatisation of the group of clients involved. For example, stigmatisation by professionals in mental health care has been shown to affect service delivery (Lauber et al. 2006, Van Boekel et al. 2013), the recovery of patients (Schomerus et al. 2011), and the accuracy of diagnoses (Thornicroft et al. 2007). Stigma is an overarching term that refers to problems of knowledge (ignorance), attitude (prejudice), and behaviour (discrimination) (Thornicroft et al., 2007).

Various reasons have been reported that can explain why care providers may hold stigmatising attitudes toward their clients. First, care providers are part of the general public. This is a sphere in which stigmatisation toward minority groups (including people with intellectual disabilities) is present and forms a subtle barrier to social inclusion (for a review: see Scior 2011). Therefore, it is possible that care providers, even though working with people with intellectual disabilities, may hold stigmatising attitudes toward people with intellectual disabilities (e.g. having similar concerns regarding the vulnerability of people with intellectual disabilities as the general public reports). Likewise, stigmatisation toward people with intellectual disabilities was found within mainstream health professionals (Pelleboer-Gunnink et al. 2017). Moreover, care providers may especially have more intense and more frequent contact with people with the highest support needs. Such clinician bias may lead to a more pessimistic view on people's life chances (Thornicroft et al. 2007, Horsfall et al. 2010, Hugo 2001). Finally, the tendency to include attitudes in the content of staff training programs is still limited, which may not benefit the awareness and combatting of stigma (Hastings 2010, Smidt et al., 2009, van Oorsouw et al., 2013). Possible stigmatisation by care providers is particularly significant when considering that staff are key agents in supporting people with intellectual disabilities to fully participate in society (e.g. Stevens and Harris 2017) and to cope with stigmatisation (Craig et al. 2002).

Two specific forms of stigmatisation might be relevant with respect to care providers: (1) public stigma, and (2) structural stigma. Public stigma refers to negative cognitions (e.g.

stereotypes) and negative emotions (e.g. prejudice), followed by discriminatory behaviour toward people with intellectual disabilities in the general public (e.g. Corrigan and Watson 2002, Link and Phelan 2001). For example, stereotypes regarding the incompetency to learn new skills (Werner 2015, Meppelder et al. 2014) may prove a challenge to people with intellectual disabilities who are seeking to enter competitive employment (Skelton and Moore 1999). With respect to the second form of stigma, staff can be supportive of social norms and policies that (un-)intentionally restrict opportunities for individuals with intellectual disabilities (i.e. structural stigma) (Corrigan et al. 2004). For example, staff members may support social norms (e.g. the belief that people with intellectual disabilities must be protected/sheltered) that may inhibit community inclusion for people with intellectual disabilities (Venema et al. 2015).

In the field of intellectual disabilities, research on stigma is limited, especially concerning care providers. Alternatively, indications of possible stigmatisation by care providers might be found in the more prevalent literature on "attitudes" of care providers regarding people with intellectual disabilities. For example, studies on the attitudes of care providers toward community inclusion may provide indications of support of social norms that restrict opportunities for people with intellectual disabilities (i.e. structural stigma) (e.g. Henry et al. 2004). This scoping review aims to (i) explore the volume and characteristics of research that may provide indications of possible stigmatisation of people with intellectual disabilities by care providers, and (ii) explore the nature of possible stigmatisation by care providers (i.e. public stigma and support of structural stigma).

The present article displays the characteristics of a scoping review. Scoping studies still lack a uniform definition, and guidelines for procedure and reporting (Pham et al. 2014). Yet, scoping reviews have been described as systematic literature reviews that aim to map primary research in a field of interest in terms of the volume, nature, and characteristics, to provide directions for future research (Arksey and O'Malley 2005). Results are presented following this scoping-review aim due to our broad research question and the highly heterogeneous nature of the available literature (Arksey and O'Malley 2005, Pham et al. 2014).

METHOD

Search strategy

A structured search was made (January 1994 to April 2017) in four databases (i.e. PubMed, PsychINFO, CINAHL, and ProQuest [i.e. Social Services Abstracts and Sociological Abstracts]) to identify relevant studies in English-language peer-reviewed journals. An update in the two main databases—PubMed and PsychINFO— was performed by the first author in February 2019. Search terms were structured following the PICO approach by specifying a population, intervention/exposure, comparison, and outcome component (Liberati et al. 2009). However, for the present study, no comparison component was specified due to the

descriptive nature of the research aim. Also, the type of study design was not conditional, since various empirical designs (including qualitative and quantitative studies) could provide relevant information related to the research aim.

TABLE 1 | *Search strategy in PubMed using Medical Subject Headings [MeSH] and text words.*

	PUBMED FINAL SEARCH STRATEGY
1	*Population: care providers*
#1	Health Personnel [MeSH]
#2	Staff [TI/AB]
#3	Service-provider* [TI/AB]
#4	**#1 OR #2 OR #3**
2	*Exposure: intellectual disability*
#5	Intellectual disability [MeSH]
#6	Mentally disabled person [MeSH]
#7	Developmental Disabilities [MeSH]
#8	Learning Disorders [MeSH]
#9	Intellectual Disab* [TI/AB]
#10	**#5 OR #6 OR #7 OR #8 OR #9**
3	*Outcomes: stigmatising attitudes*
#11	Social stigma [MeSH]
#12	Stereotyping [MeSH]
#13	Attitude [MeSH]
#14	Knowledge [MeSH]
#15	Social distance [MeSH]
#16	Social discrimination [MeSH: NoExp]
#17	Prejudice [MeSH: NoExp]
#18	Rejection [MeSH]
#19	Social Marginalization [MeSH]
#20	Attitude*[TI/AB]
#21	**#11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20**
4	*Outcomes & Exposure: stigmatising attitudes toward disability*[*]
5	*Outcomes & Population: stigmatising attitudes of healthcare providers*
#22	Attitude of Health Personnel [MeSH]
6	*Combining search term groups*
#23	**#4 AND #10 AND #21 (care providers & intellectual disability & stigmatising attitudes)**
#24	**#10 AND #22 (intellectual disability & stigmatising attitudes of care providers)**
#25	**#25 OR #26**

Note. TI/AB refers to the search for text words within title and abstract; MeSH refers to the search for Medical Subject Headings, the thesaurus terms that were used in PubMed. All thesaurus terms, unless stated otherwise, were expanded to various lower level terms. For example, the term 'health personnel' encompassed all healthcare personnel from dentists to psychotherapist to nurses. Similar search strategies were used for PsychINFO, ProQuest and CINAHL[*]Not applicable within PubMed but, for example, the thesaurus term 'attitude to disability' was used in CINAHL. The search period in all databases ranged from January 1994 to April 2017.

The *population* under study were care providers with direct client contact. This was defined as care providers working for an intellectual disabilities-service provider for whom treatment, care, or support of clients was an important part of their job description (e.g.

support staff, direct-care staff, social workers, therapists). Studies were excluded when participants were, for instance, employed as household staff, managers, or directors. "Direct client contact" was assumed to be present based on the participants' job titles and the context/information provided by each study. In case of uncertainty about the nature of participants' contacts with clients, the authors of the original article were contacted. When a mix of professionals with and without direct client contact participated in a study (e.g. care providers and managers), either the results of subgroups were reported, or in case no sub- group means were provided, results for the whole group were included, but only when statistical tests had demonstrated no significant differences on the outcome measures between the subgroups. Furthermore, all studies focusing on students were excluded.

Concerning *exposure*, studies had to focus on people with intellectual disabilities.

The *outcome* investigated in the studies had to include *public stigma* (i.e. the cognitive, affective, or behavioural dimensions by which people are viewed or treated as devalued), or *structural stigma* (i.e. support of social norms and policies that may reduce opportunities for people). Therefore, attitude studies were included when attitudes were reported that are supportive of restrictive social norms or policies (i.e. negative attitudes).

Table 1 presents an overview of the search terms and strategy applied in PubMed, using medical subject headings (MeSH) and additional text words. Our search strategy was repeatedly tested to reveal which text words were necessary (in addition to the thesaurus terms) in the aim to include all relevant studies. The following text words were added: intellectual disab*, staff, service-provider*, and attitude*. Search strategies similar to the one used in PubMed were applied in the other three databases.

Study selection

Figure 1 is a flowchart showing the process of identifying and selecting relevant studies.

In the identification phase, records were identified in four databases; then, during screening, duplicates, essays, and reviews were excluded. Next, the remaining records were independently screened on title by two reviewers (HP and PE, WvO or JvW) using the inclusion criteria (Table 2).

When all inclusion criteria were met, or when there was uncertainty about an inclusion criterion, the records were retained; this strategy resulted in 84% inter-rater agreement. Full consensus on inclusion or exclusion was reached through discussion between the reviewers. Then, abstracts were independently assessed by two reviewers (HP and WvO) based on the exclusion criteria; this resulted in 77% inter-rater agreement. Again, full consensus was reached through discussion between the reviewers. In case of complex decisions, the remaining authors (PE and JvW) were consulted. Full-text articles were assessed on exclusion and inclusion criteria by the first author. Reasons for inclusion or exclusion were then extensively discussed by two reviewers (HP and WvO) In case of lack

of clarity about the presence/absence of inclusion/exclusion criteria, the authors of the original article were contacted.

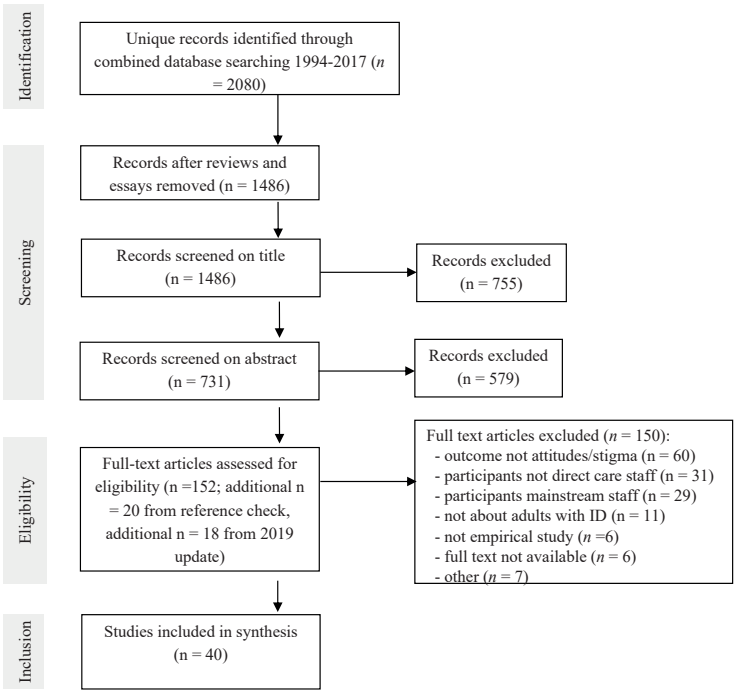

FIGURE 1 | Flowchart of the study selection process.

Moreover, the bibliographies of all eligible full-text articles were screened for additional eligible studies. Finally, the quality of studies was assessed using the multi method appraisal tool (MMAT) (Pace et al. 2012). This instrument assesses the quality of studies with various research designs, and has demonstrated good content validity and reliability (Pace et al. 2012). Appraisal was discussed by a senior researcher WvO (experienced in conducting and supervising systematic reviews) and the first author. Because of the scoping nature of the review, no studies were excluded based on quality (Pham et al., 2014). The MMAT quality appraisal format was used to retrieve descriptive quality information about each individual study.

Charting the data

Information on the following items was extracted from the studies: the country of study, study sample, research design and methods, dependent/independent variables, severity of intellectual disabilities, and the methodological strengths/limitations of the studies. In addition, data were extracted on the nature of the possible stigmatisation by care providers concerning both structural and public stigma. Table 3 presents general and methodological information derived from the studies.

TABLE 2 | *Inclusion and exclusion criteria.*

Inclusion criteria
• Participants: care providers with direct client contact working in ID services. • Outcome: results could be interpreted as public stigma (i.e., cognitive, affective, or behavioural dimensions by which people are viewed or treated as devalued) or structural stigma (i.e., support of social norms and policies that may reduce opportunities for people). • Exposure: study concerned people with ID.
Exclusion criteria
Participants: • Students • Staff without direct client contact (e.g., directors) • Mainstream health professionals[1]
Exposure: • Disability in general • Children with ID[2] • Disability possibly related to ID (e.g., acquired brain injury) but presence of ID not specified
Outcome: • Perceptions of training needs for staff • Attitudes towards specific issues like interventions, special care, special services, deviant sexual behaviour, challenging behaviour, bereavement, or prenatal screening tests • Opinions about care for people with ID • Structural discrimination (e.g., barriers in accessing health care)
General: • No original research • Studies on psychometric data (i.e., validity and reliability of a measure)

Note. [1]criterion was used within full text selection, see Pelleboer-Gunnink and colleagues (2017) for a review on studies investigating mainstream health professionals; [2]'people with ID' without specifying life stage or age, were included.

RESULTS

This review included 40 articles that reported about 39 studies; the resulting information is presented below in a narrative form (Arksey and O'Malley 2005). The main results are divided into (1) general characteristics of the studies, (2) methodological characteristics, (3) possible moderators of stigma, and (4) reported indications concerning the nature of stigmatisation (i.e. both public stigma and support of structural stigma). Concerning the latter part (i.e. the nature of stigmatisation), the support of structural stigma is described in the most detail because most studies addressed support of structural stigma and few reported on public stigma.

General characteristics of the studies

Countries

Studies were mainly conducted in Western countries: (n = 5), the Netherlands (n = 3), Ireland (n = 2), Canada that is, in the UK (n = 13), Australia (n = 7), USA Greece, Belgium,

Poland, and Italy. Two studies were (*n* = 2), and Israel (*n* = 2). Single studies were found in conducted in non-Western countries, namely Pakistan and Japan. In two of the studies, comparisons were made between two countries, which are Japan and USA, and Israel and USA, respectively.

Participants and setting

In most studies, care providers with direct client contact comprised support staff (*n* = 30). In the remaining studies, participants were specialised intellectual disabilities nurses (*n* = 3), specialised intellectual disabilities speech and language therapists (*n* = 1), mainly conducted in a combination of different settings specialised intellectual disabilities care providers (*n* = 4). Studies were social workers (*n* = 1), or a combination of different specialised intellectual disabilities care providers (*n* = 4). Studies were mainly conducted in a combination of different settings (e.g. day care, outpatient treatment, and residential services) (*n* = 14) or in an unspecified setting (e.g. client and community services) (*n* = 11). Qualitative studies mostly described the setting of a community group home (*n* = 4 out of 7 studies).

Methodological characteristics

Concerning the critical appraisal of the included studies, Table 3 provides methodological strengths and limitations for each individual study. Following, trends in methodological strengths and limitations are described.

Designs and sampling

Quantitative, cross-sectional designs were mostly used (*n* = 26), but also descriptive (*n* = 4), qualitative (*n* = 8), and mixed method (*n* = 1) designs were applied. Sampling in quantitative studies was mostly selective using convenience or opportunity samples (*n* = 21), whereby several studies sampled within one were not always reported, or were relatively limited service organization (*n* = 9 studies). Response rates were not always reported, or were relatively limited (<60%). Only within five studies a (stratified) random sampling procedure was followed. In qualitative studies, three studies used a purposive sample, and three studies presented no inclusion criteria and/or self-selection into the sample (Table 3). Thus, the sampling strategy used within studies in this field of research has significant limitations.

Measures. With the exception of three studies, two of which employed semantic differential scales (Harris and Brady 1995, Parchomiuk 2012) and the other a repertory grid technique (Hare et al. 2012), all quantitative studies used Likert-scale self-report measures of explicit attitudes. Most measures did not specifically aim to capture stigmatisation, but tended to address general attitudes. Although some validated outcome measures were used (e.g. CLAS-ID; SMRAI), most studies used self-developed questionnaires and reported only on Cronbach's alpha as a measure of internal consistency of the measure, but no other indicators of reliability (e.g. test-retest reliability) were described. Regarding qualitative

studies, semi-structured interviews (*n* = 3), focus groups (*n* = 2), open-ended questions (*n* = 1), and observations with additional interviews (*n* = 1) were used.

TABLE 3 | *Main characteristics of the included studies*.

Article	C*	D*	Setting [a]	Care providers [a]
Bazzo *et al.* (2007)	IT	1	ID residential centres, day centres, outpatient treatment services	Direct care staff (*n*=94)
Bekkema *et al.* (2014)	NL	1	Research panel of registered ID care staff; Dutch professional association of ID physicians.	ID physicians (*n*=145) Care staff (*n*=196)
Bekkema *et al.* (2015)	NL	1	Research panel of registered ID care staff; Dutch professional association of ID physicians.	ID physicians (*n*=145) Care staff (*n*=196)
Bigby *et al.* (2009)	AU	4 (3)	Community houses for 4-6 residents with severe/profound ID; staffed 24h; assistance with personal care	1- Residents-staff dyads (*n*=25) 2- Staff (*n*=8)
		4(1)	Residential, home support or day services	Direct care staff and first-line managers (*n*=144)
Christian *et al.* (2002)	US	2	ID agency providing supported living, employment and education, and day services	Full- and part time support staff (*n*=43)
Clement *et al.*(2009)	AU	3	Group home in a mixed residential and commercial neighbourhood for five middle-aged men having severe-profound ID	Support staff (*n*=7)
Crook *et al.* (2015)	UK	3	Two team bases of the learning disability service	Clinicians (*n* = 34)
Cuskelly *et al.* (2004)	AU	1	NGO supporting ID people	Support staff *(n*= 62)
Doody *et al.* (2013)	IE	3	Voluntary ID community and residential services	Registered Nurses Intellectual Disability (RNID) *(n*=7)
Evans *et al.* (2009)	IE	1	Community-based service for people with mild, moderate or severe ID	Staff carers *(n*=155)
Flatt-Fultz *et al.* (2012)	US	1	Non-profit human service agency	Direct support professionals (*n*=43)
Gilmore *et al.* (2010)	AU	1	NGOs for people with ID	Support staff *(n*=169)
Golding *et al.*(2015)	UK	3	Charitable organisation, small residential homes (5-7 residents)	Support workers/ residential care workers (*n*=20)
Grieve *et al.* (2009)	UK	1	Community residential facilities, nursing homes, hospital inpatient facilities	Staff members *(n*=188)

Outcome Instrument	Methodological strengths and limitations
Questionnaire: SMRAI (sexual rights & stereotypes subscale)	Selective convenience sample (i.e., questionnaires handed out during a meeting), measures with clear origin
Questionnaire: case-related considerations about end-of-life care, beliefs about medical interventions	Use of national research panel, response rate staff 67%, ID physicians 53%; extensive measurement description
Questionnaire: place end-of-life care for recent patient with ID, beliefs about appropriate environment for end-of-life care	Use of national research panel, response rate staff 67%, ID physicians 53%; extensive measurement description
1- Observation 2- Interviews	Mixed method with quantitative part answering question from qualitative part. Extensive description of context, sources of data and process of research. Purposive sample
Questionnaire: staff experience & satisfaction Questionnaire: community care	Opportunity sample
Questionnaire: sexual expression, reproductive rights & care; education & support	Staff of one agency, random selection, 57% response rate, measure of unclear origin
Observation, field notes, discussion of data with staff, activity logs (diary of the activities that residents had taken part in)	Context of research and influence of researcher is clearly described, clear analysis.
6 open-ended questions regarding clinician's attitudes towards research participation	Low response rate (36%), no member check or independent researchers involved in analyses, no information about impact of context on findings.
Questionnaire: attitude on sexual feelings, sex education, masturbation, relationships, intercourse, sterilisation, marriage, parenthood	Sample is unclear, one agency, no response rate provided. Clear origin of the measures used.
Semi-structured interviews: experience of caring for elderly with ID	Purposive sampling, clear analysis, participants were known to the interviewer 7 out of 20 approached nurses participated.
Questionnaire: sexuality, education & training, sexual rights, views about relationships	Select sample, response rate of staff was 41%, all staff from one agency. Origin of the measure is clear.
Questionnaire: Empowerment subscale CLAS	Convenience sample in one agency, unknown response rate, one subscale of validated questionnaire, random allocation to conditions.
Questionnaire: attitudes to sexuality (ID vs general population)	Selective sample: wide sampling in one organisation with 14% response rate, clear origin of measures.
Focus groups: attitudes covering topics of different attitude scales	Self-selection into sample without inclusion criteria. Researcher is leader and facilitator focus groups. Clear analysis procedure.
Questionnaire: sexual attitudes (homo & heterosexuality masturbation, sexual & nonsexual behaviours)	Little information about convenience sampling procedure. Not complete outcome data (29%) is removed and thereby a low response rate. Measurements are appropriate

Article	C*	D*	Setting [a]	Care providers [a]
Hare *et al.* (2012)	UK	2	Inpatient unit, adults with ID, 7 beds, 24 h support, referral for CB, medication reviews, or health	Learning disability nurses *(n*=7) Clinical support nurses *(n*=7)
Harper *et al.* (1994)	UK	1	Independent agency which was to take responsibility for accommodating over 100 people with ID following retraction of hospital.	Staff members (*n*=21)
Harris *et al.* (1995)	UK	1	ID therapists in area of Wales and South-West England. Mild or severe ID	Speech and language therapists *(n*=40)
Henry *et al.* (2004)	US/IL	1	(1) 46 US ID community residential agencies (2) 4 Israeli ID agencies	Staff *(n*=147) Staff *(n*=74)
Holmes *et al.* (1998)	UK	2	Medium secure unit with strict sexuality policy (i.e. no kissing and touching during residency) Patients of unit often suffered abuse	(Non-) clinical staff with direct-patient contact (*n*=46*)* Nurses (*n*=17); Support staff, (*n*=5); Professionals (*n*=21)
Horner-Johnson *et al.* (2015)	(1) JP (2) US	1	1) state funded residential and research institution 2) agencies operating community residences	Staff (*n*=76) Staff (*n*=151)
Jones *et al.* (2008)	CA	1	Community agencies serving people with ID	Frontline staff (*n*=166); Non-frontline staff (*n*=72)
Kordoutis *et al.*(1995)	GR	1	Greek asylum (Leros PIKPA) with inhumane circumstances international intervention team tried improvement	Care staff (*n*=70)
Lee *et al.* (2015)	UK	3	Specialist ID trust for clients with a forensic history and ID	Qualified ID nurses (*n*=9)
Maes *et al.* (2008)	BE	2	ID services in Flanders, 63.6% residential facilities, 19.7% services living independently/ with parents; group home (15.15%)	Coordinating staff members (*n*=66)
McConkey *et al.*(2000)	UK	1	Hospital and community settings; day care and residential setting	Post-qualified nurses (*n*=269) Staff in ID service (*n*=270)
Meaney-Tavares *et al.*(2012)	AU	1	Day programs, community- based services, and residential settings in metropolis for people with ID	Staff (*n*=66)
Murray *et al.* (1995)	UK	1	Client and community services	Employees working with client and community services (*n*= 246)
Murray *et al.* (1994)	CA	1	Client and community services	Employees working with client and community services within ID organisation (*n*=161)
Oliver *et al.* (2002)	US	1	Residential community settings	Direct-care paraprofessionals supporting people with ID (*n*=59)
Parchomiuk *et al.*(2012)	PL	1	Various (i.e., social work, special education)	Various, among others, social workers

Outcome Instrument	Methodological strengths and limitations
Repertory grid interview about perception of clients with ID and challenging behaviour and attributions	Selection of participants is unclear. Strong method using repertory grid technique.
Program Analysis of Service Systems (PASS); two open-ended questions	Unclear sampling strategy, measurement, and information intervention
Semantic differential scale: how is a person likely to respond in a relationship	Stratified random sample, response rate 72%, 61% complete responses, clear measurements and random allocation to condition
CLAS	Good sampling, valid measurement, but no participant-level response rate
SMRAI Open-ended questions	No information about sampling strategy
CLAS	Selective sample, valid measure
CLAS (short form)	Stratified sample by region and agency, valid measure, low response rate (41%)
Questionnaire: stereotyping and segregation attitudes	Selective sample of all care staff in one agency within very specific circumstances. Theoretically solid measures.
Semi-structured interviews: experiences working with people with ID and personality disorder (PD)	Clear method of analysis (IPA), no inclusion criteria participants, little consideration to researchers influence on the findings.
Questionnaire: accommodations & personnel, staff working methods & staff attitudes	Not clear whether sample is representative, clear theoretical framework behind measures
Questionnaire: previous contact, confidence at meeting, willingness for social contact	Opportunity sample, origin of items is clear, not clear whether groups compared hold comparable participants
Questionnaire: attitudes to sexuality (general population & ID version) sexual rights, parenting, non-reproductive sexuality, self-control	Convenience sample of staff in several organisations with low response rate (22%); clear origin of measurement
LDAIDS SPLDAI	Random sample, measures with clear origin, response rate 55%
SMRAI	Selective sample (all employees from one organisation, response rate 54%); clear origin measure.
Questionnaire: acceptability of socio-sexual behaviours: adapted from Socio-Sexual Knowledge and Attitudes Test (SSKAT)	Convenience sample, clear origin of measure, but no indication of internal consistency, not clear whether groups are comparable
Semantic differential scale: attitude towards sexuality of people with ID and physical disability	No information about recruitment participants, origin of measures, comparability of groups, and response rate.

Article	C*	D*	Setting [a]	Care providers [a]
Parkes *et al.* (2006)	UK	3	Social services day care facilities for people with ID	Staff members (*n*=9)
Patka *et al.* (2013)	PK	1	Two ID focused organisations in Karachi	Disability service providers (*n*=190)
Pebdani (2016)	US	1	Professional organization for individuals who work with ID, and state's ID service agency	Employees in group homes for people with ID (*n* = 71)
Redman *et al.* (2012)	UK	1	Learning disability service	Support staff (*n*=23)
Tartakovsky *et al.*(2013)	IL	1	NGO community services for people with ID and people with severe mental illness (SMI)	Community service workers in ID (*n*=126)
Venema *et al.* (2015)	NL	1	Residential facilities, neighbourhood with 'ordinary' non-segregation, neighbourhood with 'reversed' non-segregation	Direct support professionals (*n*=336)
Venema *et al.* (2016)	NL	1	Reversed integration project, 20 homes of 3-10 people with ID surrounded by 83 homes of general public.	Direct support professionals (*n*=28)
Wiese *et al.* (2013)	AU	3	Community group homes	Community living staff
Yazbeck *et al.* (2004)	AU	1	NGOs & government services providers	Disability service professionals (*n*=202)
Yool *et al.* (2003)	UK	3	Medium secure unit for adults with ID	Various, among others, senior care worker (*n*=1), advocacy worker (*n*=1)

Note. *C = Country; *D = Design: 1 = cross sectional; 2 = descriptive; 3 = qualitative; 4 = mixed method. Questionnaires: Community Living Attitude Scale (CLAS); Attitudes to Sexuality Questionnaire (ASQ); Attitude towards Disabled Persons scale (ATDP); Sexuality and Mental Retardation Attitude Inventory (SMRAI) The Scale of Attitudes Towards Mental Retardation & Eugenics–Revised (AMR&E-R); The Mental Retardation Attitude Inventory (MRAI); Marlowe-Crown Social Desirability Scale (MCSDS); NGO = Non-Governmental Organisation.

Outcome Instrument	Methodological strengths and limitations
Focus group interviews: sexuality and people with ID	No selection criteria for participants, method of data collection is clear, no consideration of context and researchers influence on findings
CLAS	Staff from 2 organisations, 100% response rate, valid measure
Demographics ASQ-ID	Convenience sample recruited through e-mail so no response rate or outcome data, use of validated questionnaire, no info regarding potential confounders
Questionnaire: human rights knowledge and attitudes	No information about recruitment of participants, response rate; incomplete data,
Questionnaires: CLAS, Value preference, Burnout	Random sampling from three sources (response rate 25, 60 and 40%), valid measures, correction for group differences
Questionnaire: experienced competencies, professional identity	Selective sampling (one organisation), response rate 36%, clear theoretical framework for measures, groups not comparable
Semi-structured interview: attitudes, perceived social norms about integration, meta-evaluation about work	Stratified sampling, but within one organisation; unclear validity and definition of measures, response rate 100%
Semi-structured interviews	Purposive sampling with inclusion criteria, constant comparative method of analysis, cross check of results with participants, clear consideration of influence of context on finding
Questionnaires: MCSDS, AMR&E-R, MRAI, CLAS	Selective/convenience sample, response rate 44.7, 40.75 and 50.5%. Valid measures, no correction for group differences, no complete outcome data.
Semi-structured interview: attitudes and training needs regarding sexuality	4 participants randomly selection from different profession groups, method of data collection and analysis is clear, no cross check with participants, or independent reviewers of the data.

Independent variables: possible moderators of stigmatisation

In cross-sectional studies, mainly demographic variables (e.g. gender, age, and education) were examined as moderators of attitudes; in most studies, these demo- graphic variables were not related to stigmatisation. Moreover, a minority of studies examined job-related variables, such as work setting, professional role, and prior contact with people with intellectual disabilities. Finally, three studies examined structural relations between attitudes and other outcome variables (i.e. value preference, burnout levels, social norms, effort to facilitate inclusion, experienced competencies, role identity, and meta-evaluations) (Tartakovsky et al. 2013, Venema et al. 2015, 2016).

Prior personal contact

Within stigma research, the contact hypothesis is prominent and states that becoming more familiar with a minority group relates to less stigmatisation, especially when contact takes place under positive conditions (Allport 1954, Pettigrew and Tropp 2006). Therefore, in this review we have looked into the evidence base for this hypothesis within the population of care providers. First, support staff in the included qualitative study by Golding and Rose (2015), reported that prior to working in the intellectual disabilities field, they felt that they were stigmatising people with intellectual disabilities by believing that (i) people with intellectual disabilities "did not have the ability to be independent and were like 'vegetables'," and that (ii) that they were too scared to speak to them; however, these beliefs positively changed when they started working (i.e. becoming familiar) with individuals with intellectual disabilities (Golding and Rose, 2015). Yet, care providers already working in the intellectual disabilities field will inevitably be familiar with people with intellectual disabilities to some extent. Therefore, three studies have assessed care providers' familiarity/contact with people with intellectual disabilities within care providers' personal lives, and one study addressed the quality of contact they reported with people with intellectual disabilities. One study found that care providers' regular contact with individuals with intellectual disabilities in their personal life was associated with more willingness to have con- tact with a group of people with intellectual disabilities living in their neighbourhood (McConkey and Truesdale 2000). Yet, having a friend or family member with a disability was not significantly related to attitudes toward inclusion (Patka et al. 2013), and only concerning the subscale self-control related to attitudes toward sexuality (Pebdani, 2016). Self-reported quality of contact with persons with intellectual disabilities was not related to attitudes toward sexuality (Murray et al. 1995). Thus, having personal contact with people with intellectual disabilities might have positive effects on care provider's attitudes, however, evidence is still inconclusive.

Severity of the disability

Given the diversity in the population of people with intellectual disabilities, it is relevant to examine whether the nature of stigmatisation by staff differs according to different levels of impairment. Of the 40 articles in this review, 30 did not provide details on the severity of the intellectual disability (Table 4), in six articles the severity of the intellectual disability was specified, and in five articles staff outcomes were related to the severity of the disability. These comparison studies indicated that higher levels of stigma are found when participants are asked to answer questions regarding individuals with severe intellectual disabilities as compared to those with mild intellectual disabilities. For example, Bigby et al. (2009) demonstrated that, irrespective of a general agreement with principles of choice and inclusion, staff found it difficult to envision that this can be applied to people with severe intellectual disabilities or people with challenging behaviour. Moreover, Harris and Brady (1995) reported that people with mild intellectual disabilities were more positively perceived within a relationship (e.g. more kind) than were people with severe intellectual

disabilities (e.g. more selfish). Finally, no studies addressed other variables known to influence stigmatisation, such as the concealability of the disability, or the degree to which the disability/stigma impedes social interactions.

TABLE 4 | *Articles that reported on the level of intellectual disability.*

Level of intellectual disability	No. of articles	Method of indicating /using the level of intellectual disability within studies	Main findings	Authors
Not specified	30			
Mild-moderate	1	Respondents were instructed to answer questions with respect to people with a mild to moderate intellectual disability.	Generally positive attitudes towards sexuality, more cautious about parenting, less sexual freedom for women with than without ID	Gilmore & Chambers 2010
Moderate	1	Support staff respondents were asked to answer the items considering an 'adult with moderate support needs and an Intelligence Quotient of 40-55".	Generally positive attitudes towards sexuality, less so about parenthood, parents more conservative than staff	Cuskelly & Bryde 2004
Severe-profound	3	Qualitative study including staff working with people with severe-profound ID	Service delivery based on community presence not participation, staff adhered different meaning to inclusion than policy meaning; inclusion felt not feasible due to differentness of clients	Clement & Bigby 2009
		Studies were conducted in a context where the majority of the people were having severe to profound ID or ID and behaviour and/or psychiatric problems	Mean of attitudes towards inclusion is relatively negative (below mean). The effort to support inclusion is moderate or slightly positive. Attitudes towards inclusion are a significant predictor of effort to facilitate inclusion.	Venema *et al.* 2015
Severe-profound	3	Studies were conducted in a context where the majority of the people were having severe to profound ID or ID and behaviour and/or psychiatric problems	Half of staff were positive about integration (50%), a third were negative (32.1%) and 17.9% neutral. Staff with positive attitudes stressed advantages of integration like contact with neighbours; staff with negative attitudes stressed restrictions due to integration (e.g., less freedom of movement); and that integration does not work for specific groups, e.g., those with ID and behaviour problems/ psychiatric problems. Staff with a neutral attitude were positive about the idea, but stated that results were negative in practice.	Venema *et al.* 2016

Level of intellectual disability	No. of articles	Method of indicating /using the level of intellectual disability within studies	Main findings	Authors
(a) Severe-profound (b) comparison	1	(a) Ethnographic study of support staff working in a group home for people with severe intellectual disability; (b) participants were asked to think of an individual they knew, to say whether this person had mild or moderate or severe and profound intellectual disability	Staff doubt offering opportunities for choice/ participation would make any difference; residents seen as childlike; dismissive behaviour of residents' purposeful choices; physical design of the house (e.g. separate toilet staff and residents) showed them-us value; ideas inclusion ridiculed. Clients did not participate more among others because degree of impairment of residents. Participants with general ID version scored higher than participants with the individual version (people rating a person they knew). Worse attitudes for people with severe/ profound ID or challenging behaviour.	Bigby *et al.* 2009
Comparison	4	Scenario's describing a person with mild or severe intellectual disability	In relationships, people with mild ID seen positive (e.g., kindly, truthful, confident); 16 of 19 agreed relationship be encouraged. Severe ID viewed negatively (e.g., selfishly, false, shy); 4 of 21 believed relationship would succeed with support.	Harris & Brady 1995
		Support staff answered questions relating to people with mild, moderate or severe/ profound intellectual disability	Mean scores around possible median score of scale. Attitudes more positive for heterosexuality than homosexuality. Mean attitude scores decrease with level of ID. No significance testing	Grieve *et al.* 2009
		Comparison mild/ moderate vs severe/ profound, no explanation about criteria for level	Decisions about medical interventions: wishes-preferences of people with mild/ moderate were taken into account more often (27.8%) than the wishes/preferences of people with severe/profound ID (2.9%).	Bekkema *et al.* 2014
Comparison	4	Comparison of mild, moderate, and severe levels; no explanation about indication of levels in questions	Liberal staff attitudes towards sexuality. Acceptance of non-intimate relationships for all ID levels (63-90%). People with ID (79%), family (73%), staff (70%) should be involved in decisions about relationship; 25% unsure whether to entitle privacy (i.e., unsupervised relationships); 21% unsure whether inform family about relationship. Less acceptance for severe vs moderate vs mild ID of intimate relationships (8% vs 25% vs 55%); or marriage (5% vs 15% vs 48%).	Evans *et al.* 2009

Nature of stigmatisation

Table 5 thematically presents the main outcomes of all individual studies.

Public stigmatisation

Concerning the nature of possible stigmatisation, six studies described elements of public stigma by care providers (e.g. stereotypes, prejudice, and discrimination). These studies mainly discussed the presence of stereotypical perceptions of people with intellectual disabilities (n = 5). For example, Hare et al. (2012) examined how care providers perceive clients with intellectual disabilities who show challenging behaviour. They concluded that the team of care providers did not hold a collective or stereotyped view of their clients, but showed a high degree of variability in how they construe their clients (Hare et al. 2012). Besides the relatively positive finding of non-stereotypical perceptions in this study from the UK, other studies indicated the presence of stereotypical views of people with intellectual disabilities. For example, Kordoutis et al. (1995) described clear stereotyping and segregation attitudes in a very specific situation in the Leros asylum in Greece. In that situation, a three-year deinstitutionalization and rehabilitation pilot-intervention project was implemented due to the appalling conditions at the asylum: residents suffered severe deprivation, extreme institutionalization, and violation of basic human rights (see, Tsiantis et al. 2000). In those deprived situations, people with intellectual disabilities were, for example, viewed as "unhappy," and as if "they cannot manage even their simplest needs" (Kordoutis et al. 1995). Moreover, when focusing on particular stereotypes regarding "people with intellectual disabilities being in a relationship," people with mild intellectual disabilities were viewed more favourably (e.g. kindly, truthful or confident) than those with severe intellectual disabilities (e.g. more selfish, false, shy) (Harris and Brady 1995).

In addition to stereotypes regarding intellectual disabilities, staff may have stereotypical perceptions of people with intellectual disabilities based on other social identities. For example, Lee and Kiemle (2015) suggested, based on their findings that, in case of comorbidity of both a personality disorder and intellectual disabilities, the complexity of the personality disorder seemed to minimise the relevance of intellectual disabilities. Staff, for example, mainly attributed negative traits (like "unpredictable," "insecure," "self-centred," "lacking in empathy") to the personality disorder and not the intellectual disabilities of their clients. Also, Maes and Van Puyenbroeck (2008) demonstrated that some staff members held stereotypical attitudes toward elderly patients with intellectual disabilities based on ageist assumptions (e.g. people should have the opportunity to slow down and be inactive), that may limit the range of opportunities that are offered to older people with intellectual disabilities.

Only the study by McConkey and Truesdale (2000) did not focus on cognitive aspects of public stigma but on staff's behavioural intentions. The authors found that care providers did not differ from mainstream nurses in terms of the amount of contact they had with people with intellectual disabilities in their personal lives, as well as their willingness to

engage in social contact with people with intellectual disabilities. In summary, studies concerning public stigma were scarce and mainly focused on the cognitive aspects of stigma (i.e. stereotypes). Evidence was found for the presence of both stereotypical and non-stereotypical views on people with intellectual disabilities among care providers. In addition, based on two studies, there is preliminary evidence that care providers may hold stereotypical views on people with intellectual disabilities based on other social identities, such as personality disorders or being elderly. Regarding behavioural intentions, specialised intellectual disabilities care providers appeared not to differ from mainstream nurses.

TABLE 5 | *Overview of themed stigmatising attitude outcomes.*

Article	Stigmatising attitudes – outcomes
	Public stigma
Hare *et al.*	Team no stereotyped view of clients with challenging behaviour. Different meanings to internal and external causes of CB, clients with internal and external causes of behaviour not construed systematically different. Construal of whole person with history most relevant to understanding behaviour.
Harris *et al.*	In relationships, people with mild ID seen positive (e.g., kindly, truthful, confident); 16 of 19 agreed relationship be encouraged. Severe ID viewed negatively (e.g., selfishly, false, shy); 4 of 21 believed relationship would succeed with support. *Level of ID* more negative towards severe ID.
Kordoutis *et al.*	Strong negative attitudes. (e.g. [range =1-6, 1 = totally agree] it is better if they do not associate with normal people [$M = 1.90$, $SD = 1.36$]; They cannot manage even their simplest everyday needs [$M = 2.46$, $SD = 1.41$]).
Lee *et al.*	Negative traits were mainly attributed to personality disorder (PD). The disorder was overriding the disability because the complexity of the PD minimised the relevance of ID. Staff stressed the importance of getting to know the client behind the labels (ID & PD). This appeared to protect from damaging consequences of the label.
Maes *et al.*	Three views supported by different staff regarding support elderly with ID; (1) encouragement of participation and involvement in activities and relationships (2) stereotypical attitudes about elderly, e.g., should slow down and be inactive (disengagement) can result in lower expectations and ageist assumptions (3) utilizing specific methods and activities.
McConkey *et al.*	Scores above the mean in confidence at meeting people with ID (e.g., 30% of the nurses and therapists and 42% of ID staff answer 'definitely yes' to the question 'feel confident'). Positive scores on willingness for social contact in their personal lives with people with ID. **Therapists vs nurses vs ID staff** ID staff more confident meeting people with ID; no differences in willingness social contact. **Physical disability vs ID** therapists and nurses more confident meeting people with physical disability than ID. For ID professionals no difference.
	Community inclusion
Bigby *et al.*	Staff doubt offering opportunities for choice/participation would make any difference; residents seen as childlike; dismissive behaviour of residents purposeful choices; physical design of the house (e.g. separate toilet staff and residents) showed them-us value; ideas inclusion ridiculed. Clients did not participate more among others because *degree of impairment* of residents.

Article	Stigmatising attitudes – outcomes
	Level of ID Participants with general ID version scored higher than participants with the individual version (people rating a person they knew). Worse attitudes for people with severe/profound ID or challenging behaviour.
Clement *et al.*	Support staff interpreted inclusion in various ways but differing from the official meaning of community participation. Support staff had 'problems' with the aim of community participation, the pace or the aim itself was seen as not feasible. Staff did not consider themselves to be part of the education process of the general public to include people with ID. Impossibility of participation was also attributed to personal characteristics of clients due to institutionalizations or being too different. People with ID were seen as not ready for community participation and need to get ready in the distant future. Staff's view on leisure (weekend, evening, day) influenced how staff approached community participation, a consequence was that activities were often group based. Staff did not know how to build relationships for the men in the house.
Doody *et al.*	Inclusion within society crucial for elderly in being valued members of their community; familiarity may improve societal attitudes; importance of seeing person rather than disability: individualised approach supported, personal aspects that allow for individuality such as personal belongings.
Flatt-Fultz *et al.*	Mean score of 33 on the empowerment subscale for the group that did not receive training.
Golding *et al.*	Working with ID made attitudes more positive, before lacked knowledge and afraid to speak with people with ID; attitudes towards integration were positive; staff believed it was possible to offer people with ID choice in everyday life as long as the person has the capacity to make informed choice. Balance between protection and empowerment; staff admitted they become over protective because people with ID are vulnerable. Only the theme 'impacts of integration is sufficiently represented in attitudes scales.
Harper *et al.*	In response to the question how you would describe people with learning difficulties benevolent and patronizing responses were found. Staff perceived it important for people with ID to be present within the community as it would increase choice, more individual care, and more opportunities for activities.
Henry *et al.*	Positive attitudes towards community living. Mean scores high for similarity subscale; low on exclusion subscale and neutral on sheltering and empowerment.
Horner-Johnson *et al.*	No multivariate differences between Japan and USA when adding potential confounders to the model; for empowerment lower and for sheltering higher scores for Japanese staff. Older staff more likely to endorse sheltering and less likely to endorse similarity.
Jones *et al.*	In general, respondent's attitudes consistent with ideals of inclusion. Yet, for some items a large proportion showed attitudes that are not according to inclusion philosophy especially concerning empowerment or sheltering.
Patka *et al.*	Attitudes generally positive with high mean scores on similarity; below average mean scores on exclusion and neutral scores on sheltering and empowerment. *Staff vs community* staff had higher scores on empowerment and similarity and lower scores on exclusion and sheltering than community members.
Tartakovsky *et al.*	High scores on value of power was related to lower levels of empowerment and similarity and higher levels of exclusion. Self-direction and similarity positively related; benevolence and similarity positively related. *ID vs SMI workers* ID workers lower levels of empowerment and similarity, and higher levels of exclusion and sheltering.

Article	Stigmatising attitudes – outcomes
Venema *et al.*	Mean of attitudes towards inclusion is relatively negative (below mean). The effort to support inclusion is moderate or slightly positive. Attitudes towards inclusion are a significant predictor of effort to facilitate inclusion.
Venema *et al.*	Half of the support staff were positive about integration (50%), a third were negative (32.1%) and 17.9% were neutral. Staff with positive attitudes stressed the advantages of integration such as contact with neighbours; staff with negative attitudes stressed the restrictions that were due to integrations (e.g., less freedom of movement); and that integration does not work for specific groups, e.g., those with ID and behaviour problems/psychiatric problems. Staff with a neutral attitude were positive about the idea, but stated that results were negative in practice.
Yazbeck *et al.*	Generally, positive attitudes to community inclusion. Low on exclusion, above the mean on similarity, and neutral on empowerment and sheltering subscales. *Students vs community vs professionals* On all attitude scales, more positive attitudes disability service staff and students than general community. Also on subscales sheltering, exclusion, similarity, empowerment, integration /segregation, social distance, privacy and rights, subtle derogatory beliefs.
	Sexuality
Bazzo *et al.*	Staff demonstrated moderately liberal attitude towards sexuality. Staff in outpatient treatment services most liberal. No norm for 'liberal' provided.
Christian *et al.*	Most respondents have positive attitudes, e.g., 93% of respondents agreed women with ID have similar sexual desires as women without ID and 90.7% agreed sexuality is important part of who a women is. Some agreement with restrictions: 24% agreed sterilization be supported as method of birth control.
Cuskelly *et al.*	Generally, positive views regarding sexual expression of people with moderate ID. No norm provided. More conservative concerning parenthood than other aspects. *Parent vs staff vs general community* Parents more conservative than staff, but not when corrected for age.
Evans *et al.*	Liberal attitudes of staff towards sexuality for people with ID. No norm provided. Acceptance of non-intimate relationships for all ID levels (63-90%). People with ID (79%), family (73%), staff (70%) should be involved in decisions about relationship; 25% unsure whether to entitle privacy (i.e., unsupervised relationships); 21% unsure whether inform family about relationship. *Staff vs family* Staff more liberal. *Level of ID* Less acceptance for severe vs moderate vs mild ID of intimate relationships (8% vs 25% vs 55%); or marriage (5% vs 15% vs 48%).
Gilmore *et al.*	Generally positive attitudes towards sexual rights, parenting, non-reproductive sexual behaviour and self-control. Least positive about parenting. *Support staff vs leisure workers* Similar attitudes, on parenting support staff more conservative. *ID versus non-ID* Higher level of sexual freedom appropriate for non-ID than ID. Only applies to women with ID.
Grieve *et al.*	Mean scores around possible median score of scale. Not tested for significance but attitudes more positive for heterosexuality than homosexuality. *Level of ID* Not tested for significance, mean attitude scores decrease with level of ID.
Holmes *et al.*	Generally, liberal attitudes towards sexuality. The 16% of staff who said that intimate relationships between clients should never be allowed were mainly nurses; clients should always be permitted access to condoms (support staff = 100%; other professionals = 90%; nurses = 69%); should always be allowed to masturbate in private (100% nurses agreed).

Article	Stigmatising attitudes – outcomes
Meaney-Tavares *et al.*	Attitudes toward sexuality of people with ID were generally positive. However, although no significance test of difference, the attitudes toward sexuality of the general population appeared to be more positive.
Murray *et al.*	Staff attitudes towards sexuality highly liberal. Liberal attitudes towards sexuality related to positive attitude to people with ID and AIDS. On item-level also negative: 11.8% of staff agrees people with ID should be stopped from sexual activity to reduce risk AIDS. Similarly, 44.1% of staff agrees with mandatory testing for HIV.
Murray *et al.*	Staff members reported a moderately liberal attitude towards the sexuality of people with ID with considerable variation (range = 35-100)
Oliver *et al.*	Staff demonstrated significant differences on acceptable socio-sexual behaviour between people with and without ID only for marriage and childcare, but not for example concerning kissing, petting, or masturbating.
Parkes *et al.*	Participants felt angry and frustrated when clients are denied opportunities to express their sexuality. Participants empathised with clients in some cases by comparing themselves to them.
Pebdani	Mean scores were not interpreted by the authors, but seemed relatively positive. Having an immediate family member with ID was related to more positive attitudes towards self-control of people with ID but no difference on sexual rights, parenting and non-reproductive sexual behaviour.
Yool *et al.*	Liberal attitudes to sexuality and masturbation, privacy must be provided. Sexuality seen as shared common need; experienced similarly by people with and without ID. Less liberal towards sexual intercourse, homosexual relationships, and involvement of adults with ID in decisions about sexuality. Client's involvement in decisions dependent on *level of understanding*; ability to express sexuality and ability to provide consent.
	Decision-making and being informed and involved
Bekkema *et al.*	Decisions about medical interventions: wishes-preferences of people with mild/moderate were taken into account more often (27.8%) than the wishes/preferences of people with severe/profound ID (2.9%).
Bekkema *et al.*	Despite belief of care staff that wishes of persons with ID should always be leading in deciding of place of care, only 8% of the care staff and ID physicians mentioned that the wishes of the client were taken into account in actual decisions. Wishes of the client were 6th in the most mentioned considerations about where to receive end-of-life-care after (expertise of team, familiarity with the environment, equipment, possibility to employ extra caregivers, wishes/preferences of family members).
Wiese *et al.*	Staff unanimously supported the belief that people with ID should know about dying. Yet, clients were hardly involved in the topic.
Crook	Clinicians suggested that people should not be excluded from research because of their ID. However, clinicians reported reluctance to signposting service users to projects if the research intentions are not clear, or if they see no direct benefits for people with ID thereby possibly preventing them from involvement in research.
	Other
Redman *et al.*	Staff had high attitude scores (also pre-training) towards human rights.

Structural stigma

The largest number of studies (*n* = 33) provided indications of the support of structural stigma. Regarding the focus of these studies, two issues were prominent, namely

community inclusion and sexuality. In addition, three studies (as presented within four articles) addressed the attitudes of care providers to processes of decision-making by people with intellectual disabilities and being informed and involved, and finally, one article reported on human-rights knowledge of staff (Redman et al. 2012).

First, within articles addressing community inclusion (n = 14), in a general sense, this inclusion was valued as important for people with intellectual disabilities (Doody et al. 2013, Golding and Rose 2015). For example, in the study by Golding and Rose (2015), care providers were generally positive about integration and believed that both the individual with intellectual disabilities and society would gain from integration. Moreover, based on outcomes from the Community Living Attitude Scale (CLAS; n = 7), care providers showed no desire to exclude people with intellectual disabilities from community life (i.e. in all studies, the subscale "exclusion" received the lowest mean score) and care providers unanimously perceived people with intellectual disabilities as being similar to themselves (in all studies, the highest mean score). For example, Henry et al. (2004) reported on the CLAS (note: in other studies referred to as CLAS-MR or CLAS-ID [Henry et al. 1996]) (6-point and high scores on similarity (M = 4.81). Similarly, on scale, Mdn = 3.5) low scores on exclusion (M = 1.68) item level, there was clear consensus on items of the exclusion and similarity subscales (e.g. 95% of staff disagreed that homes/services for people with intellectual disabilities should be kept out of residential neighbourhoods [exclusion subscale]; and 93.4% agreed that people with intellectual disabilities have goals for their lives just like other people [similarity subscale]) (Jones et al. 2008).

However, care providers demonstrated ambivalent attitudes (i.e. scores inclined toward the mean "not agree/not dis- agree") toward sheltering (i.e. belief that people must be protected) and empowerment (i.e. support of self- advocacy and empowerment). For example, Henry et al. (2004) reported close to neutral scores on sheltering (M = 3.43) and empowerment (M = 3.97). Jones et al. (2008) showed a similar indecisiveness on item level, (e.g. 23.7% of staff disagreed with the statement that "the opinion of people with intellectual disabilities themselves should carry more weight than those of their family members and professionals," in decisions affecting that person [empowerment subscale]); moreover, 48.1% agreed that sheltered workshops for people with intellectual disabilities are essential [sheltering subscale]). Similarly, Golding and Rose (2015) reported that care providers acknowledge being overprotective and concluded that care providers care providers needed to find a balance between protection and empowerment.

Moreover, four of the 14 studies clearly indicated the scepticism of staff with regard to community inclusion. That is, in two Australian studies, care providers working in comparable community-based group homes in one geographical area, doubted the feasibility of the principles of community inclusion, choice, and participation for people with severe/profound intellectual disabilities (Bigby et al. 2009, Clement and Bigby 2009). Reasons for non-feasibility were, for example, that the implementation of such

principles would make no difference for people with severe intellectual disabilities, that people are too different, or that they are not ready for inclusion (Bigby et al. 2009). Moreover, Venema et al. (2015, 2016) conducted two studies in the Netherlands with care providers working in a reversed integration setting (i.e., a setting in which people without intellectual disabilities purposefully choose to live next to people with intellectual disabilities). In these studies, conducted in one geographical area with staff working with people with high support needs, staff held relatively negative attitudes toward integration. They mentioned several perceived disadvantages of integration, such as the possibility of a decreased freedom of movement compared to residential areas. That is: *"In contrast to the residential facility, in the reversed integration setting there were "regular" traffic movements and because the clients were unfamiliar with the traffic rules, they were not allowed to go outside on their own anymore."* Moreover, staff assumed that neighbours in a reversed integration setting held less positive social norms regarding integration than the neighbours themselves actually held (Venema et al. 2016). Similarly, Golding and Rose (2015) reported that, when specifically asked, care providers discussed potential harms to society by integrating people with intellectual disabilities in the community such as physical harm, or feeling intimidated and frightened. Moreover, Clement and Bigby (2009) reported that activities for people with intellectual disabilities guided by care providers were focused on community presence, not participation.

Thus, concerning community inclusion, care providers seem to hold a generally positive attitude. When looking for possible support of social norms and policies that restrict opportunities for people with intellectual disabilities (stigma), there are indications that care providers judge community inclusion to be less feasible for specific groups of people with intellectual disabilities (i.e. those with behavioural or psychiatric problems, and people with severe/profound intellectual disabilities) (Bigby et al. 2009, Venema et al. 2015). Moreover, there was a tendency for care providers to be ambivalent about whether people with intellectual disabilities should be protected or empowered (e.g. Golding and Rose, 2015).

Second, studies concerning possible structural stigma related to the sexuality and parenthood of people with intellectual disabilities (n = 14) focused on a large variety of aspects, such as sexual rights, masturbation, intercourse, sexual education, marriage, relationships, homosexuality, and parenthood. Attitudes of staff were mainly discussed as being either liberal or conservative, with most results being interpreted as (moderately) liberal. For example, liberal attitudes referred to the agreement that sexuality is an important aspect of a person's life and that people with intellectual disabilities have sexual desires similar to those of people without intellectual disabilities (Parkes 2006, Christian et al. 2002). Nevertheless, care providers seemed to be more positive toward the sexuality of people from the general population than toward the sexuality of people with intellectual disabilities (Gilmore and Chambers 2010, Meaney-Tavares and Gavidia-Payne 2012). For example, Gilmore and Chambers (2010) demonstrated that, on issues related to access to sexual education, contraception and freedom of sexual expression, care providers saw

more freedom as acceptable for women without intellectual disabilities than for women with intellectual disabilities. This relationship was not found for men with and without intellectual disabilities. Also, Christian et al. (2002) demonstrated that liberal attitudes do not necessarily indicate that the support of people with intellectual disabilities regarding sexuality is a high priority. That is, 44% of staff felt that when providing support to women with intellectual disabilities, there were more important priorities to focus on than sexuality (Christian et al. 2002).

Concerning homosexual relationships and parenthood, care providers seemed to hold more ambiguous views. Care providers expressed uncertainty about how to deal with homosexual relationships compared to heterosexual relationships (Yool et al. 2003) and were less positive about parenthood compared to other aspects of sexuality (Gilmore and Chambers 2010, Cuskelly and Bryde 2004). Moreover, some staff members seemed to support restrictions related to mandatory HIV testing (44% of staff agreed with mandatory testing for people with intellectual disabilities) (Murray et al. 1995). Additionally, care providers seemed to hold ambiguous attitudes toward both privacy and self-determination in terms of sexuality. For instance, about 25% of the care providers were not sure whether people with intellectual disabilities should be allowed to have unsupervised relationships, or whether to inform parents about their adult child's intimate relationships (Evans et al. 2009). Finally, intimate relationships were viewed as less acceptable for people with severe compared to mild intellectual disabilities (Evans et al. 2009, Harris and Brady 1995); moreover, care providers deemed the individual's level of understanding as relevant to the acceptability of sexual relationships, as well as involvement in decisions about the individual's own sexuality (Christian et al. 2002, Yool et al. 2003).

In summary, sexuality was a prominent theme and staff seemed to hold mostly liberal attitudes toward sexuality of people with intellectual disabilities, although some restrictive or ambiguous attitudes were present. Indications of possible stigmatisation were found regarding homosexuality, parenthood, the priority of sexuality in support, privacy, and self-determination concerning sexuality.

Finally, a Dutch study [(Bekkema et al. 2014, 2015)], an Australian (Wiese et al. 2013), and a British one (Crook et al. 2016) examined staff attitudes, as well as their behaviour related to processes of decision- making and being informed and involved. It was demonstrated that agreement with certain social norms/ human rights did not automatically lead to staff following-up on such rights. That is, care providers were highly likely to believe that clients' wishes should always be leading in terms of decisions about the place of end-of-life care and they believed this more so than intellectual disabilities physicians and general practitioners. Nevertheless, in the end, only 8% of the respondents reported the wishes of the client as an actual consideration in the decision about the place of end-of-life care (Bekkema et al. 2015). Similarly, although staff working with elderly people with intellectual disabilities felt that people with intellectual disabilities have the right

to know about dying, clients were hardly ever engaged in this topic (Wiese et al. 2013). Also, clinicians feel that people with intellectual disabilities should not be excluded from research. Yet, a suspicion of research intentions, or not perceiving immediate of direct benefits for a client, can prevent clinicians from allowing people with intellectual disabilities to participate in research (Crook et al. 2016). Moreover, in medical decision-making, the wishes/preferences of people with mild/moderate intellectual disabilities were taken into account more often (27.8%) than the wishes/preferences of people with severe/profound intellectual disabilities (2.9%) (Bekkema et al. 2014).

DISCUSSION

This scoping review was systematically conducted to identify studies that may address possible stigmatisation by care providers toward people with intellectual disabilities. The aim was to provide an overview of these studies in terms of general characteristics, methodology used, moderators of stigma, and indications concerning the nature of the stigmatisation.

Given the ubiquity of stigmatisation, it seems especially relevant to address stigmatisation in relation to care providers who have direct client contact. Obtained knowledge may help care providers to enact their key role in the lives of people with intellectual disabilities. Stigmatisation was conceptualised as either public stigma (i.e. stereotypes, prejudice, and discrimination) or support of structural stigma (i.e. social norms and policies that restrict opportunities for people with intellectual disabilities). Due to the lack of research on stigma in the field of intellectual disabilities, our exploration of possible stigmatisation by care providers included the more prevalent literature on "attitudes" and related concepts (e.g. beliefs). However, because these studies did not explicitly aim to address stigmatisation, any interpretations regarding possible stigmatisation of staff should be made with caution.

The 40 studies included in the review were mainly conducted in Western countries, with care providers working either in unspecified intellectual disabilities settings or a variety of different settings (e.g. day care, residential). A minority of studies considered care providers other than support staff (e.g. therapists, nurses, or social workers), the majority of studies focused on support staff. Studies mostly did not differentiate between varying levels of intellectual disabilities. Most studies used self-report Likert-type measures of explicit attitudes; this has been reported before by, for example, Antonak and Livneh (2000). Several studies were conducted in a forensic setting, which might have coloured the experiences and perceptions of staff working in these specialised institutions. For example, staff's perceptions may have been influenced by clients' criminal behaviour and the environmental/procedural restraints of the secure setting, as well as their intellectual disabilities.

Studies related to public stigma were scarce. Two studies showed that care providers may stigmatise people with intellectual disabilities based on other social identities (e.g.

in case of comorbidity, a person's personality disorder was found to be more strongly stigmatised than the person's intellectual disabilities). This issue of intersecting identities may need further research, especially considering the fact that an intellectual disability is often viewed as a dominant social identity (e.g. Beart et al. 2005, Logeswaran et al., 2019). Concerning the presence of stereotypical perceptions of people with intellectual disabilities, both the presence and absence of stereotypes were demonstrated. All studies (except for one on behaviour/ behavioural intentions) focused on cognitive aspects of public stigma. Studies on the possible support of structural stigma mainly focused on aspects of community inclusion, sexuality, and parenthood. Of note, some alternative, current, and relevant themes were scarce (e.g. decision-making, or being informed) or even missing (e.g. employment and social networks).

There was scepticism regarding the feasibility of community inclusion for clients with high support needs. Care providers tended to be ambivalent about whether people with intellectual disabilities should be protected or empowered. This finding is specifically relevant, given the fact that people with intellectual disabilities have reported experiences of over-protection, lack of recognition, and dependence on support as important expressions of stigmatising treatment (e.g. Jahoda and Markova 2004, Jahoda et al. 2010, Giesbers et al. 2019). Possible indications of stigmatisation regarding sexuality were found on issues related to parenthood, homosexual relationships, priority of supporting sexuality, sexuality-related privacy, and self-determination; these issues may warrant more research into possible support of structural stigma. Furthermore, stigmatisation seemed to be related to subgroups of people with intellectual disabilities and appeared to be the strongest for people with severe/profound intellectual disabilities, and people with high support needs (including people with challenging behaviour, or comorbid psychiatric diagnoses). Finally, agreement of staff with certain rights, such as (informed) decision-making, did not necessarily lead to staff acting in accordance with such rights.

Implications for clinical practice

Due to the key role of care providers, their continuous training and coaching in maintaining high-quality levels of support is essential. Based on the present results, attention for the potential presence and influence of stigmatising attitudes on the quality of care providers' support seems needed. The tendency to include care providers' attitudes in the content of staff training programs is how- ever, still limited in the field of intellectual disabilities (Hastings 2010; Smidt et al. 2009; Van Oorsouw et al. 2013). Comparably, in the field of mental illness, interventions that address stigmatisation by mental health professionals are also uncommon (Thornicroft et al. 2016). The few interventions that were found in the field of mental illness, concerned information-based approaches that resulted in short-term improvements in knowledge and behaviour (Thornicroft et al. 2016). Therefore, a first step may be to raise awareness concerning the relevance of stigmatisation and attitudes in the context of services that are provided to people with intellectual disabilities (Embregts 2011; Pijnenborg et al. 2016; United Nations 2006).

There is, however, limited evidence concerning what might follow this first step to raise awareness. In all healthcare fields, the question what might constitute effective elements of training that can reduce stigmatisation of care providers are hardly explored. Yet, leads for future development of interventions can, for example, be derived from the general reference point that stigmatisation can only exist in a context of power difference (Goffman 1963, Link and Phelan 2001). Given the inevitable power difference that does exist in the relationship between care provider and service user (client), it seems important that care providers are willing to share their power (e.g. by shared-decision making) and to listen carefully to clients and their families/ network (Douglas and Bigby 2018, Pijnenborg et al. 2016). This may reduce the demonstrated risk on over- protection and limited involvement in decision-making for people with intellectual disabilities. For this purpose, out of many possibilities, the approach of experience-based co-design might, for example, be useful (e.g. Bate and Robert 2006), because it facilitates the exchange of experiences between service users and care providers with the aim to improve the quality of services. Also, working together with experts-by-experience in individual sup- port questions of service users toward more independence, may prove specifically helpful because of its empowering function (Pijnenborg et al. 2016). A second lead for future development of interventions, concerns the potential risk on diagnostic overshadowing which is often related to stigmatisation (e.g. Evans-Lacko et al., 2010). Diagnostic overshadowing concerns a tendency to overlook symptoms of mental health or physical problems and attribute them to being part of "having an intellectual disability" (Mason and Scior, 2004, Werner et al., 2013). Care providers (e.g. support staff) in the field of intellectual disabilities often have a signalling function of mental and physical health symptoms toward health professionals and may therefore contribute to diagnostic overshadowing by overlooking relevant symptoms. In staff coaching, the advices regarding diagnostics in relation to stigmatisation as made by Pijnenborg et al. (2016) may prove relevant: (1) try to place symptoms in a normalizing framework, (2) do not insist on people accepting the diagnosis (of intellectual disabilities/personality disorder), but validate emotions and symptoms, (3), do not stress biomedical factors in discussing a client's diagnosis but stress the potential to improve and learn.

A final implication concerning what support staff may need to maintain high quality levels of support, was found within studies concerning attitudes toward community inclusion. Two of these studies demonstrated that support staff struggle to interpret the meaning of broad and often not specifically defined policy principles (e.g. community inclusion) or display uncertainty in terms of how to apply such principles to specific groups of people (e.g. people with severe intellectual disabilities) (Bigby et al. 2009, Clement and Bigby 2009). Therefore, staff may need explicit, practical information regarding policy principles concerning human rights, possibly in combination with on-the-job coaching to convey latest knowledge to the daily support of individual clients (Van Oorsouw et al. 2009).

Implications for research

Concerning future research, studies on staff's expression of public stigma are currently limited in both number and scope. Addressing not only cognitions, but also emotions and behaviour of staff, may provide directions for staff training. Moreover, studies on staff's support of structural stigma have mainly focused on sexuality and community inclusion, while other issues are scarcely represented. For example, Stevens and Harris (2017) indicate that attitudes of care providers are pivotal in creating a positive (or negative) climate when supporting people to get and keep jobs (Stevens and Harris 2017). Future research into staff's possible sup- port of restrictive social norms regarding employment may prove to be a fruitful effort to improve an individual's opportunity for employment. Additionally, several other issues, such as friendships, social networks, self- determination, valued leisure activities, or physical health, may also benefit from this focus (e.g. Wong and Wong 2008).

Related to methodology, mostly Likert-type self-report studies or qualitative thematic studies into explicit attitudes were employed. Future observation studies or proxy reports can have the additional potential to address behavioural presentations of stigma that care providers may not be aware of or either may not be willing to report. Moreover, given the complex nature of the process of stigmatisation, it seems meagre that only Likert scales are used to assess internal processes. Numerous alternatives to Likert-type scales have been described (e.g. q-methodology, adjective checklists, rankings, socio-metrics, qualitative methods) that may increase the validity of the conclusions drawn from existing studies (Antonak and Livneh 2000, Haddock and Zanna 1998). Moreover, to obviate the threats of validity inherent to explicit measures of stigma/attitudes (e.g. social desirability bias, generosity effect), implicit methods such as the quantitative implicit association test, qualitative causal layered analysis, may prove valuable (Antonak and Livneh 2000, Dorozenko et al. 2015). Finally, most studies did not differentiate between subgroups of people with intellectual disabilities. Given the large diversity within the total group of people with intellectual disabilities, and the indications that stigma might vary for different sub- groups of people with intellectual disabilities, future studies might benefit from using vignettes or examining real-life situations to explore the impact of (for example) the concealability of intellectual disabilities, or the amount of deviant behaviour on stigmatisation by care providers.

The present study has some limitations. The exclusion of grey literature and studies published in languages other than English may have caused a bias toward significant results and information from specific regions of the world. Also, as this review covers research from around the world the recommendations are generic. Therefore, some issues may be of local concern rather than a widespread issue and might need further exploration in local conditions. Finally, this study focused on care providers as participants of studies. Future review study might focus on the reports of clients and relatives about their care providers' attitudes to complete the picture.

CONCLUSION

Care providers are key agents in supporting people with intellectual disabilities to achieve valuable life goals. To provide high-quality support, staff should receive training not only to improve the level of their knowledge and skills, but also to address the possible presence of stigmatisation. It is of foremost importance to raise awareness of the relevance of stigmatisation in the context of services provided to people with intellectual disabilities. Moreover, care providers should be encouraged to share power with people with intellectual disabilities and their families, for example, in working together with experts-by-experience. Also, the accurate use of diagnostic information is relevant to prevent diagnostic overshadowing. More studies on public stigma may provide new directions for staff training regarding stereotypes, prejudice, and discrimination. Preferably, future studies into support of structural stigma among care providers, should address a wider range of life domains (e.g. employment).

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Chapter 7

General Discussion

Amo, volo ut sis
-- Tomáš Halík

Nowadays in the Netherlands, people with intellectual disabilities mainly live within community settings. This is the result of deinstitutionalisation policies that were developed with the intention to advance participation and inclusion of people with intellectual disabilities within mainstream society (Woittiez, Eggink, Putman, & Ras, 2018). Physically living within the community has opened opportunities for contact between people with and without intellectual disabilities, and resulted in higher levels of participation, for example in undertaking activities in the community (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). However, living within the community also holds the risk of increased experiences of stigmatisation by people with intellectual disabilities (Bredewold, 2014; Cooney, Jahoda, Gumley, & Knott, 2006). Moreover, irrespective of the gains regarding inclusion, it has been proved difficult to achieve a real inclusive society where people with intellectual or other disabilities fully participate (Kröber, 2008; Woittiez et al., 2018). There remain abundant barriers for example in monetary income, employment, social networks, access to housing, access to healthcare, and access to education (Bowey, McGlaughlin, & Saul, 2005; Emerson, 2007; Giesbers, Jahoda, Hastings, Hendriks, & Embregts, 2018; Krahn, Hammond, & Turner, 2006; Reindal, 2010). Stigmatisation is an underestimated problem that can explain experiences of limited participation and inclusion (Scior et al., 2016).

THE PRESENT THESIS

The overall aim of this thesis was to expand knowledge about the stigma concerning people with intellectual disabilities, specifically by exploring the nature and level of stigma as found within the general public. In the first part of this thesis, we examined the Dutch general public's views about people with intellectual disabilities by (1) using a high quality-population sample (Chapter 2 and 3), and (2) a study with an exploratory character in which we examined which assigned characteristics distinguish people with intellectual disabilities from the general public (i.e., stereotypes; Chapter 4). The second part of this thesis reported on the systematic review of current literature (Chapters 5 and 6) regarding stigma in two subsamples of the general public, namely (1) mainstream health professionals (Chapter 5) and (2) care providers working in intellectual disabilities service organisations (Chapter 6). These subsamples of the general public were chosen because health professionals and care providers can play a key role in people's opportunities for inclusion within healthcare and society. Therefore, stigmatisation by these groups may have particularly adverse effects. This final chapter (Chapter 7) consists of the following elements: a summary of the main findings, a general discussion of the findings, discussion of limitations and strengths of this thesis, directions for future research, implications for policy and practice, and finally a concluding remark.

SUMMARY OF MAIN FINDINGS

Part 1: Dutch general public's views about people with intellectual disabilities

In the first part of this thesis we aimed to draw a clearer picture of the Dutch general public's views about people with intellectual disabilities. The results of a population survey are described in Chapters 2 and 3, the results of an exploratory study in Chapter 4.

Within *Chapter 2* we started by examining a fundamental cognitive aspect of stigma, namely the reported stereotypes regarding people with intellectual disabilities. We studied (1) the appearance and salience of stereotypes, and (2) how these stereotypes related to discriminatory intentions and familiarity. First, we have demonstrated with factor analysis of a Likert-type scale that the general public seems to hold a set of four main stereotypes concerning people with intellectual disabilities. The demonstrated stereotypes represented both a positive and negative valence, namely: "friendly", "in need of help", "unintelligent", and "nuisance". An open-ended question was analysed to corroborate the salience of the stereotypes. "Friendly", "in need of help", and "unintelligent" were found to be salient stereotypes due to their frequent report in the open-ended question. In accordance, in the open-ended question, we have searched for stereotypes that may be complementary to the demonstrated set of stereotypes. Stereotypes that were not identical nor synonyms of the stereotype items in the Likert scale, but complementary, mainly referred to areas of dependence and incompetence; for example, being "less independent" "having low levels of social skills", and "having an impairment in thinking" were the most frequently reported.

Second, we have examined two relationships with stereotypes: (a) whether being familiar with people with intellectual disabilities would relate to the strength of the stereotypes, and (b) whether the strength of the stereotypes could predict levels of discrimination. Concerning familiarity, we found that participants who were not familiar in real life with people with intellectual disabilities considered them to be less "in need of help" and more of a "nuisance" compared to participants who reported real-life familiarity with people with intellectual disabilities. Concerning discrimination, participants reported low levels of discriminatory intentions (i.e., low levels of social distance and a high intention to show helping behaviour). Yet, a stronger "friendly" stereotype predicted lower levels of discrimination, while, contrarily, a stronger "nuisance" or "unintelligent" stereotype predicted higher levels of discrimination.

Within *Chapter 3,* we have focused on (1) the role of the general public's familiarity with people with intellectual disabilities in predicting stigma and (2) the mediating role that their emotions may play in the relationship between familiarity and discrimination. First, we have demonstrated that two thirds of the Dutch population sample in this study does report to be familiar with people with intellectual disabilities in any form, while one third does report that they have no familiarity in real-life with people with intellectual

disabilities (i.e., at its best: participants indicated they saw a documentary about people with intellectual disabilities). Members of the general public who were unfamiliar with people with intellectual disabilities in real life, demonstrated higher levels of stigma on measures of attributions, emotions, and discriminatory intentions, than people who reported any form of real-life familiarity. People who reported familiarity within their private lives reported higher levels of sympathy regarding people with intellectual disabilities than people who reported less familiarity.

Second, Chapter 3 showed that when emotions were taken into account, no direct effects of familiarity on levels of discrimination were found. Yet, emotions mediated the relationship between reported levels of familiarity with people with intellectual disabilities and discrimination. Fear was found to be the strongest mediator. That is, being more familiar with people with intellectual disabilities predicted lower levels of fear towards them, which in turn predicted lower levels of discrimination. Concerning sympathy, a mediation effect was only found for people who reported familiarity in private life whereby higher levels of sympathy explained less social distance and more intention to help.

In *Chapter 4,* we have extended the population study on stereotypes (Chapter 2) by an exploratory study within a stratified convenience sample of the general public. In this study, we aimed to examine which assigned characteristics distinguish people with intellectual disabilities from the general public (i.e., stereotypes); thereby, we have used a percentage technique to extend research with Likert-scales. Characteristics that most strongly distinguished people with intellectual disabilities from the general public (i.e., strongly stereotypical) involved areas of dependency and incompetence (e.g., 'have difficulty learning', 'are in need of help', 'are slow', 'are vulnerable'). Similarly, characteristics that were strongly counter-stereotypical (i.e., much higher scores for the general public than for people with intellectual disabilities) concerned stereotypes of competence and independence (e.g., 'are independent', 'are able to work in a paid position'). Warm and friendly characteristics were found stereotypical but less strong than the incompetent characteristics. Characteristics referring to people with intellectual disabilities as a nuisance were not (strongly) stereotypical. No relationship between levels of familiarity with people with intellectual disabilities and the strength of stereotypes was found in this study.

Part 2: Indications of stigma among health professionals and care providers

The second part of the thesis, as described in Chapter 5 and 6, aimed to further explore stigma in the general public by focusing on two subgroups in the general public that can have an important role in the wellbeing of people with intellectual disabilities, namely: mainstream health professionals, and care providers working in intellectual disability service organisations.

In *Chapter 5* we focused on mainstream health professionals as an important subsample of the general public. Mainstream health professionals are members of the general

public that play a paramount role in access to and quality of mainstream healthcare. They could hold specific stigmatising attitudes that need targeted interventions. The results of this systematic review (*n* =30) showed that stigmatising attitudes towards people with intellectual disabilities are found among mainstream health professionals. A lack of familiarity with and knowledge about people with intellectual disabilities was found. Moreover, people with intellectual disabilities were perceived as different compared to other patients and as well as childlike funny, strange or intimidating. Mainstream health professionals reported either low or unrealistic high expectations of the capabilities of people with intellectual disabilities, for example, breast cancer screening staff reported low expectations about peoples understanding and awareness of breast care, the ability to self-examine and attendance for screening. Health professionals also reported stress, lack of confidence, fear, and anxiety in caring for them. For example, general practitioners reported a lack of confidence in treating people with intellectual disabilities as a main issue leading to frustration. A tendency to treat people with intellectual disabilities differently from other patients and a lack of addressing autonomy of people with intellectual disabilities was reported. For example, there was a common misguided assumption among accident and emergency nurses that carers could consent to treatment and care on behalf of an adult with intellectual disabilities. In addition, mainstream health professionals were ambiguous in their willingness to change and adapt their daily-care practices to people with intellectual disabilities, such as adapting communication or allowing patients with more time.

Within *Chapter 6,* we have demonstrated, in a scoping review (*n* = 40), that indications of public and structural stigma can be found amongst care providers working in intellectual disability service organisations. The included studies in this review were, mainly conducted in Western countries, and mostly not differentiating between levels of intellectual disabilities. Among all care providers involved in the lives of people with intellectual disabilities (e.g., therapists, psychologists, support staff), most studies focused on daily support staff. The majority of studies used self-report Likert-type measures of explicit attitudes and studies related to public stigma (i.e., cognitive, emotional, behavioural aspects of stigma) were scarce and mostly focused on cognitive aspects of stigma. Concerning indications of public stigma, two studies showed that care providers may stigmatise people with intellectual disabilities based on other social identities (e.g., in case of comorbidity, a person's personality disorder was found to be more strongly stigmatised than the person's intellectual disability). Both the presence and absence of stereotypes were demonstrated. Indications were also found for support of structural stigma (i.e., social norms and policies that (un-)intentionally restrict opportunities for people). These studies mainly focused on aspects of community inclusion, and sexuality. There was scepticism regarding the feasibility of community inclusion for clients with high support needs. Care providers tended to be ambivalent about whether people with intellectual disabilities should be protected or empowered. Possible indications of stigmatisation

regarding sexuality were found on issues related to parenthood, homosexual relationships, and priority of supporting sexuality, sexuality-related privacy, and self-determination. Furthermore, stigmatisation by care providers seemed to be related to subgroups of people with intellectual disabilities and appeared to be the strongest for people with severe/profound intellectual disabilities, and people with high support needs (e.g., people with challenging behaviour, or comorbid psychiatric diagnoses). Finally, agreement of care providers with certain rights, such as (informed) decision-making, did not necessarily lead to care providers acting in accordance with such rights.

DISCUSSION OF THE FINDINGS

In the following section, three main points are discussed that follow from the results of this thesis. First, the findings of this thesis point towards the ambivalent nature of intellectual disabilities' stigma. This ambivalent nature indicates that discriminatory outcomes might be found more clearly in passive harm, neglect, and difficulties in addressing intergroup inequalities. Second, especially for people with mild intellectual disabilities, real life experiences of stigma might not correspond to the general public's response to the label intellectual disabilities. Third, intergroup contact theory with a focus on familiarity and the emotion of fear holds relevant for the stigma of intellectual disabilities.

Context of the findings: Western, high income societies

Before starting with the discussion of the findings, one notion needs to be made. There is abundant evidence that intellectual disabilities' stigma affects a number of life domains associated with wellbeing, such as monetary income, safety, education, employment, community inclusion, intimate relationships, and self-determination (Ditchman, Kosyluk, Lee, & Jones, 2016). The findings of this thesis aimed to contribute to tease out the nature, dimensions, and level of public stigma and provide indications how this stigma might challenge people's opportunities. Yet, essential to note is the fact that although stigma affects the lives of people regardless of country or socioeconomic level, the nature and process of stigma can differ across cultures and countries (Scior et al., 2020). The first part of the present thesis concerns a population study about public stigma in the Netherlands and within the second part of the thesis, most studies that were included in the review concerned articles that were conducted within Western, and high income countries. Therefore, the present findings about the nature and process of stigma should be interpreted within the setting of Western societies.

Ambivalent nature of stigma might challenge through passive harm

In this Western context, the findings of the present thesis demonstrate that the nature of the general public's cognitive, emotional, and behavioural responses to the label intellectual disabilities is ambivalent. The responses of the general public contain both positive and negative elements. For example, the general public's response embraced

both positive and negative stereotypes (Chapter 2); it included positive emotions (e.g., sympathy) as well as an important mediating role for a negative emotion (i.e., fear) (Chapter 3). Also, although low levels of discriminatory intentions were found in the general public, clear support of structural stigma that restrict people's opportunities were found in subsamples of the general public (Chapter 4 and 5). These ambivalent responses are different from the stigma that has been demonstrated regarding other minority groups, for example for people with mental illness (i.e., negative stereotypes have been shown to provoke discrimination, which appears as avoidance or withholding help) or people from ethnic minorities (i.e., Fiske, 2012; Reavley & Jorm, 2011; Rüsch, Angermeyer, & Corrigan, 2005). Ambivalent stigma may pose challenges for people with intellectual disabilities more so in particular forms of passive harm rather than in the form of active exclusion and harassment.

This ambivalent nature of stigma correspond to findings of previous studies in for example Canada, the United Kingdom, and Israel, where also low levels of preferred social distance were reported (McConkey, 2015; Morin, Rivard, Crocker, Boursier, & Caron, 2013; Ouellette-Kuntz, Burge, Brown, & Arsenault, 2010; Scior & Furnham, 2011; Werner, 2015). Researchers have attributed these low levels of stigma to several explanations, both methodological (e.g., threats of validity and social desirability (Ouellette-Kuntz et al., 2010) and conceptual (e.g., attitudes that are improved over time by community inclusion and increased familiarity (Morin et al., 2013; Werner, 2015); or the use of social control strategies other than stigma such as tolerance (i.e., people do notice the deviance of a condition yet they actively try to suppress the negative feelings aroused by it or minimise exposure to it by, for example, avoiding contact) (van Alphen, 2011; Dijker, van Alphen, Bos, van den Borne, & Curfs, 2011).

We would like to discuss the line of reasoning that, due to the ambivalent nature of stigma, we might need to focus on other discriminatory outcomes (e.g., passive harm) than the outcomes that are mostly studied now. We discuss two theories that provide directions regarding the discriminatory outcomes of ambivalent stereotypes. These theories align with the results of the two studies in this thesis concerning stereotypes (Chapter 2 and 4).

The first theory, is the theory of *Stereotyping by omission* as proposed by Bergsieker, Leslie, Constantine, and Fiske (2012) and implies that discriminatory outcomes of ambivalent stereotypes might be especially found in outcomes such as disregard of needs, lack of addressing inequalities, and an inapt positive view of the situation of this group of people. Research into this theory has demonstrated that when the general public holds ambivalent stereotypes (i.e., stereotypes with both positive and negative valence) like the ones we found for people with intellectual disabilities, people have the tendency to address only positive stereotypes ('friendly') and omit negative stereotypes ('dependent, slow'). This omission of negative stereotypes may have an adverse effect. That is addressing only positive stereotypes may increase the perceived harmony between groups (i.e., "We are

having fun together", "Everything is fair and 'cosy'") while making it more difficult to address intergroup inequalities (Saguy, Tausch, Dovidio, & Pratto, 2009). On an institutional level this might lead to having limited access to necessary resources, or disregard of the needs of people (Cuddy, Fiske, & Glick, 2007; Tuffrey-Wijne et al., 2014).

Second, the *BIAS (Behaviors from Intergroup Affect and Stereotypes)-map theory* leads to a similar conclusion. This theory proposes that for people with intellectual disabilities with strong incompetence stereotypes (Chapter 2 and 4) behavioural responses might be found in forms of passive harm (Cuddy, Fiske, & Glick, 2007). Cuddy, Fiske and Glick (2007) proposed the BIAS map theory, and found evidence that in general, warmth stereotypes determine active behavioural tendencies whereas competence stereotypes determine passive behavioural tendencies. That is, warmth stereotypes diminish active harm (e.g., harassing) and elicit active facilitation (e.g., helping). For people with intellectual disabilities with strong 'warmth' stereotypes, this implies a response of helping (active facilitation) and not so much of harassing. However, competence stereotypes diminish passive harm (neglecting) and elicit passive facilitation (associating). For people with intellectual disabilities with low competence stereotypes (high incompetence stereotypes), this implies a response of passive harm. Passive harm can be found in forms of neglect, diminishing social worth, social aggression, paternalising behaviour, or difficulty to address intergroup inequalities. In this context, the concept of micro aggressions (i.e., "the everyday verbal, nonverbal, and environmental slights, snubs, or insults, whether intentional or unintentional, which communicate hostile, derogatory, or negative messages to target persons based solely upon their marginalised group membership") might warrant investigation (Peters, Schwenk, Ahlstrom, & McIalwain, 2017).

Practical examples of discriminatory outcomes as proposed by these theories were found in the review studies that we conducted (Chapter 5 and 6). We will name a few examples of these discriminatory outcomes that align with this reasoning. That is, within Chapter 5, we have addressed stigma by mainstream health professionals. Among mainstream health professionals there was a consensus that people with intellectual disabilities have the right to be treated in mainstream healthcare practice and very few explicitly harassing attitudes were found. However, there were several findings that indicated some form of neglect or nonchalance that lead to discrimination in the form of not providing differential treatment according to the needs of people with intellectual disabilities. For example, there was reluctance to adjust their daily care practices to the needs of people with intellectual disabilities; and also a lack of familiarity with or knowledge about people with intellectual disabilities was reported. There were indications that mainstream health professionals showed insufficient support of autonomy and decision making of people with intellectual disabilities by for example, focusing on the care provider accompanying people with intellectual disabilities to gain information because it was seen as more efficient (e.g. Gill, Stenfert-Kroese, & Rose, 2002; Sowney & Barr 2006; Nagarajappa et al. 2013). Also, Sowney and Barr (2006) reported that, for accident and emergency unit

nurses, there was a common but misguided assumption that care providers could consent to treatment and care on behalf of an adult with intellectual disabilities. This could be interpreted as forms of passive harm.

Within Chapter 6, similarly, indications for stigma by care providers working in intellectual disability service organisations could also be placed within the framework of passive harm (i.e., neglect, not taking people seriously, not addressing inequalities). A clear example concerns the studies of Bekkema, de Veer, Wagemans, Hertogh, and Francke (2014; 2015) that 'counted' the number of times people with intellectual disabilities were actually involved in decision regarding their medical situations (Bekkema et al., 2014) or decisions about moving in the end-of-life period (Bekkema et al., 2015). These studies demonstrated that the involvement of people with intellectual disabilities in these decision was very limited despite positive attitudes of care providers regarding their involvement.

Thus, especially the ambivalent nature of intellectual disabilities stereotypes might lead to challenging discriminatory outcomes such as passive harm, neglect, and difficulties in addressing intergroup inequalities. Therefore, research into public stigma concerning people with intellectual disabilities in Western countries may profit from including and operationalizing measures of suchlike discriminatory tendencies. Measures that might provide potential starting points are measures with respect to benevolence (people are childlike and need to be cared for) or authoritarianism (people are irresponsible, so life decisions should be made by others) (Brockington, Hall, Levings, & Murphy, 2000; Corrigan, Watson, Byrne, & Davies, 2005). Moreover, research into the support of structural stigma seems especially relevant as these studies (Chapter 5 and 6) provide practical indications where stigma can be found. Studying forms of passive harm may also more easily relate the experiences of people with intellectual disabilities of a devalued identity to levels of public stigma (Jahoda et al., 2010). As well, it provides indications concerning anti-stigma interventions which will be discussed later in this chapter.

Vulnerability of people with mild intellectual disabilities: do public expectations fit public experiences?

The second notion regarding the findings of this thesis concerns the fact that the general public might not include people with mild intellectual disabilities within their interpretation of the label 'intellectual disabilities'. In this thesis, as well as in previous studies, the general public does not report stereotypes such as 'a nuisance', 'criminal', or 'can be aggressive' as salient for people with intellectual disabilities (Chapter 2 and 4; Werner, 2015). Contrarily, these stereotypes are found to be salient in the general public concerning people with mental illness (Angermeyer & Matschinger, 2005). Yet, in real-life, there is frequent comorbidity with mental illness in people with intellectual disabilities (Matson & Shoemaker, 2011), whereby, often, the intellectual disability has the master status (i.e., people with intellectual disability and comorbid mental illness; and not people with mental illness and comorbid intellectual disability). Also, for people with

mild intellectual disabilities there is a higher crime and nuisance rate compared to the general population (Fogden, Thomas, Daffern, & Ogloff, 2016). Therefore, the general public's view of low levels of nuisance, criminality, and aggressiveness of people with intellectual disabilities may not correspond with reality. A main reason is that the general public might not include people with mild intellectual disabilities within their perception of the label 'intellectual disabilities'. Scior and colleagues (2013) have demonstrated limited recognition of mild intellectual disabilities by the general public (i.e., only 35% of the respondents in their study recognised an 'intellectual disability' as an explanation for the behaviours in the presented vignette). Moreover, the general public demonstrated a milder response concerning the label (providing participants with the label of an intellectual disability with the vignette), than concerning the symptoms (not providing the label with the vignette) of mild intellectual disabilities (Scior et al., 2013).

As a result the general public's response towards people with mild intellectual disabilities in real-life might well differ from their response to the label 'intellectual disabilities'. That is, when the general public encounters reality with more nuisance than expected, this might lead to more negative reactions in real-life situations (Ali, King, Strydom, & Hassiotis, 2016). Correspondingly, in the results of this thesis (Chapter 6) we found that care providers demonstrated stronger stigmatisation concerning people with high support needs (including people with psychiatric comorbidity) and people with personality disorders. For people with mild intellectual disabilities, although they are possibly not always explicitly aware of it, there might be an accompanying dilemma regarding disclosure of their disability. This dilemma can be an important issue of intervention. In everyday situation, it might represent a choice of either the intellectual disability going unnoticed, and being misjudged and more negatively treated by the general public due to misattribution to other stigmatising causes that lead to more active harm; or being labelled and recognised as someone with an intellectual disability, and being stigmatised more so in the form of passive harm (e.g., paternalisation, losing autonomy, and being neglected). Future research should address the relevance of this dilemma for this group of people. Moreover, we might want to develop support guides for people with mild intellectual disabilities and their support workers in this respect, especially considering the fact that an intellectual disability is often viewed as a dominant social identity (Beart et al., 2005; Logeswaran, Hollett, Zala, Richardson, & Scior, 2019).

Intergroup contact theory: limited familiarity with people with intellectual disabilities and the important role of fear

Thirdly, as with other minority groups, the intergroup contact theory seems to hold significant value for the stigma concerning people with intellectual disabilities. This follows from the central role of familiarity as well as the emotion of fear that was demonstrated in this thesis. We have demonstrated in Chapter 3 that the number of people who report to be unfamiliar with people with intellectual disabilities in real-life within the Dutch population (i.e., about a third) is still substantial. This is especially relevant in light of the finding that

participants with no familiarity in real life reported higher levels of stigmatisation. Also in previous studies, prior contact with people with intellectual disabilities was related to lower levels of stigmatisation (Blundell et al., 2016; Werner, 2015; Wilson & Scior, 2015). The finding of a third of the population being not familiar in real-life is striking given the fact that for people with mild and moderate intellectual disabilities, 92% of the population are living in community settings and more than 90% of them are doing groceries themselves (Meulenkamp et al., 2015). As was noted before, this might lead us to think that people are not always recognised as someone with an intellectual disability (Scior et al., 2013) or that the community spaces where people reside are still segregated. But more important, it indicates that physical integration does not automatically lead to recognition and encounters in communities. Thereby, familiarity with people with intellectual disabilities does not automatically improve, and stigma is not automatically reduced by physical integration.

Concerning public anti-stigma interventions, these results support a focus on increasing the general public's familiarity with and knowledge about people with intellectual disabilities. After all, participants in this thesis who only reported 'familiarity in passing by' already showed lower levels of stigmatisation than people reporting no familiarity in real life. Bigby and Wiesel (2019) suggest that within mainstream society 'convivial encounters' (i.e., fleeting or more sustained encounters in daily live with for example neighbours, shopkeepers, and bus-drivers) may especially help people with intellectual disabilities to 'be recognised' and 'become known' (Bigby & Wiesel, 2015, 2019; Bredewold, Tonkens, & Trappenburg, 2016; Wiesel & Bigby, 2014). Yet, for both people with and without intellectual disabilities, situations with built-in boundaries (e.g., walking the dog, going to the shop, small-talk on the street) were most likely to lead to fruitful encounters (Bredewold, Tonkens, & Trappenburg, 2016). However, it is questionable whether these encounters alone are also fruitful in reducing passive harm, neglect, and forms of paternalisation. In the implications for policy and practice we will discuss additional cues for interventions.

In Chapter 3, it was also demonstrated that especially the emotion of 'fear' mediates the relationship between familiarity and discrimination. This aligns with stigma research following from the intergroup-contact theory (Allport, 1954; Pettigrew & Tropp, 2006). Pettigrew and Tropp (2006) discuss in a meta-analysis that especially reducing intergroup anxiety can achieve reductions in stigmatisation following from contact (e.g., Paolini et al., 2004). In their discussion, intergroup anxiety refers to feelings of threat and uncertainty that grow out of concerns about how one should act, how one might be perceived and whether one will be accepted. Also, in the field of intellectual disabilities, there are indications that fear and anxiety may play a role in establishing reactions towards people with intellectual disabilities (Pelleboer-Gunnink et al., 2017; Scior, Connolly, & Williams, 2013). Thus, it seems reasonable to assume that, concerning people with intellectual disabilities, increased positive outcomes of anti-stigma contact interventions could be achieved to the extent that anxiety is reduced (Pettigrew & Tropp, 2006). Future intervention studies

should consider incorporating measures of anxiety to further explore if and how contact interventions affect levels of anxiety concerning people with intellectual disabilities, and to explore whether decreasing anxiety might improve intervention outcomes. It may be relevant to focus in contact interventions on members of the general public that report no real-life familiarity with people with intellectual disabilities (targeted stigma-interventions). Especially for this target group, contact interventions might reduce stigma through less fear.

STRENGTHS & LIMITATIONS OF THIS THESIS

A main strength if this thesis concerns the use of LISS panel data to examine levels of public stigma. By using this high-quality population sample with a good response rate, the results provide descriptive information on a population level. This type of studies is hardly conducted in the field of in intellectual disabilities. However, these studies are essential to develop sound knowledge concerning public stigma. This knowledge is needed for the development of evidence-based stigma interventions. Another strength of this thesis concerns the theory base whereby we made use of existing stigma models and theories. As was addressed within the introduction section, and also found in the review studies (Chapter 5 and 6), most research in the area of intellectual disabilities' stigma is founded in attitude research and oftentimes lacks a theory base (Werner, 2016). By making use of existing stigma models we hope to contribute to the development of stigma theory concerning people with intellectual disabilities. This theory could inform anti-stigma interventions and may, thereby, on the long term contribute to the wellbeing of people with intellectual disabilities. In this thesis we have aimed to specifically contribute to knowledge about stereotypes regarding people with intellectual disabilities, the role of familiarity and emotions, and indications for stigma in health professionals and care providers.

In addition to these strengths, this thesis has some relevant limitations. First, all studies have focused on direct self-report of stigma by the general public (i.e., the perceivers' side of stigma); we have looked into self-report (studies) both within the general public survey studies, as well as within the review studies. Although this was a grounded choice, the apparent limitations concern the fact that in any field of research there is always a risk on social desirability in the answers, a limited relationship with actual behaviour, and attitude distorting influences (Antonak & Livneh, 2000).

Another limitation of the survey studies within the general public (Chapter 2 and 3) concerns the exclusively descriptive and cross-sectional nature of these studies. That is, in these studies, participants were merely provided with the label 'intellectual disabilities', and their reaction towards this label was assessed. Thereby, these studies provide fundamental insight into people's reaction to the plain label 'intellectual disabilities' without any explanation or confounding with other variables. However, experimenting

with different vignettes or different levels of intellectual disabilities could have provided additional insights into the constituents of the intellectual disabilities stigma (Alphen, Dijker, Bos, Borne, & Curfs, 2012; Scior, Connolly, & Williams, 2013). Also, due to the absence of explanation about the definition of intellectual disabilities, there is a risk that participants might have had an incorrect interpretation of the term 'intellectual disabilities' (e.g., as mental illness). Moreover, due to the cross-sectional nature of the survey, conclusions about causal directions cannot be drawn based on the data. For example, in Chapter 3, familiarity, emotions and discrimination have been found to be related; but there are potential alternative explanations in the order of these variables (e.g., with emotions driving both familiarity and discrimination).

Moreover, a limitation that has appeared more strongly during the process of research concerns the use of measures and concepts that have been borrowed from research within the field of mental illness. The relevance of using existing stigma concepts and measures have been thoroughly described (Ditchman et al., 2013). However, the nature of intellectual disabilities' stigma appeared to be different from the nature of mental illness stigma. Therefore, as was noted before in this discussion section, especially behavioural outcomes should be more specifically selected on relevance for people with intellectual disabilities.

Finally, in this thesis, we did not include any study concerning experiences of stigma by people with intellectual disabilities themselves. These studies have been undertaken by others (e.g., Ali et al., 2015; Cooney et al., 2006; Giesbers et al., 2018) Also, we did not systematically involve people with intellectual disabilities in the design and interpretation of the studies. Especially within the context of stigma, where the flipside of the stigma coin is called 'empowerment', undertaking the study as an inclufsive research project would have strengthened the thesis in relevance as well as in 'practice what you preach' (Bigby et al., 2014; Embregts, Taminiau, Heerkens, Schipper, & Van Hove, 2018; O'Brien, McConkey, & García-Iriarte, 2014). Although not systematically, and not reported in the studies, people with intellectual disabilities have been interviewed as part of the design of the study, and as part of the interpretation of the studies.

DIRECTIONS FOR FUTURE RESEARCH

Intellectual disabilities stigma is a largely unexplored area, therefore, conducting more scientific research into this field is anyhow essential to improve wellbeing for people with intellectual disabilities. Specifically, two notes may follow from the present thesis.

First, within Chapter 6 we have not only examined cognitive, emotional, and behavioural constituents of public stigma, but also looked into indications for structural stigma (i.e., attitudes that care providers may hold that can restrict people's opportunities in life). We have noted that research that provided indications for structural stigma focused on a few specific topics (i.e., mainly community inclusion and sexuality) and that other,

equally relevant topics, were scarce or missing (e.g., employment; decision-making). Thereby, we may overlook structural stigma regarding other issues and topics such as employment, access to information, or self-determination. Studies into a broader range of attitude-topics that relate to structural stigma may thus be needed as well as studies into structural stigma/barriers itself. For example, studies should examine whether the attitudes of care providers are supportive of competitive employment, yet, we also need studies that examine what rules and regulations may (un)-intentionally form a barrier toward employment (e.g., Pelleboer-Gunnink, Brummel, van Weeghel, & Embregts, 2018).

Meanwhile, the topics that are relevant for people with intellectual disabilities are not yet settled. Reasoning from a capability approach's perspective, it is essential to start by exploring the views and values of people with intellectual disabilities and their representatives (See also: Pelleboer-Gunnink, van Weeghel, & Embregts, 2014; Pelleboer-Gunnink et al., 2018). They should be asked what their essential valuable life goals are, and where there are (structural) barriers to reach those goals (Beernink-Wissink, 2015; Hästbacka & Nygård, 2019). That means, what life goals (topics, issues) are valued by people with intellectual disabilities? From this starting point, we can study how stigma may form a barrier in achieving these life goals (Pelleboer-Gunnink et al., 2018).

Second, as we have already mentioned there is an urgent need to develop valid measurement instruments that are specific for the assessment of stigma of people with intellectual disabilities. To date, in the field of intellectual disabilities, measurement scales have mainly focused on attitudes rather than stigma concepts, have been outdated, or 'borrowed' from the field of mental illness where the nature of stigma is different (Werner, 2016). However, there are several studies, including the ones in this thesis, that make evident that the stigma experienced by people with intellectual disabilities is strikingly different from the stigma experienced by people with mental illness (e.g., attributions of dangerousness, personal responsibility, stereotypes of friendliness, social distance). Thereby, there is a need for researchers in the field of intellectual disabilities to develop endemic stigma tools and measurement instruments. Some work is done in this regard, for example, a literacy scale has been developed (Scior & Furnham, 2011). Comparatively, however, there seems to be more attention concerning attitudes towards specific issues (e.g., sexuality and community inclusion). Therefore, on these topics measures are available (e.g., Community Living Attitude Scale [CLAS], Sexuality Attitudes Questionnaire [SAQ]). Moreover, in studies, there is a tendency to assess cognitive components of stigma/attitudes and omit the emotional or behavioural components. Especially concerning the behavioural components, there seems to be an important lack of valid instruments to be able to capture forms of passive harm (e.g., paternalising stigma). Qualitative research could offer insights into essential elements of valid stigma measurement instruments by providing a deeper understanding of the stigma of people with intellectual disabilities.

IMPLICATIONS FOR POLICY AND PRACTICE

The findings of this thesis may suggest some directions, in addition to the existing preliminary evidence regarding anti-stigma interventions concerning people with intellectual disabilities. There is currently sparse input for public anti-stigma campaigns regarding people with intellectual disabilities. However, we can take leads from anti-stigma initiatives within psychiatry as the principles of intervention might similarly apply to all minority groups (Van Weeghel, Pijnenborg, Van 't Veer, & Kienhorst, 2016).

Raising awareness: stigma is ubiquitous and not only 'others' who stigmatise

A first elementary aspect when combatting stigma in any form is to raise awareness about the relevance of stigma in the lives of people and its impact on their wellbeing (United Nations, 2006). That is, without awareness of the relevance of (public) stigma for people with intellectual disabilities, there is no urgency to address this issue. In a European report it was demonstrated that in the Netherlands, participants reported themselves to feel at ease with persons with disabilities, but they perceived 'others' in the Netherlands to feel much more uncomfortable in the presence of people with disabilities (European Opinion Research Group [EORG], 2001). This corresponds with another study that demonstrated that the general public does report low levels of discomfort in the presence of people with intellectual disabilities for themselves (McConkey, 2015). Thereby, there is a strong risk that the general public agrees that intellectual disabilities stigma is unwanted, but they mainly point towards 'others' who are negative about people with intellectual disabilities. Yet, stigma is ubiquitous (Goffman, 1963), and can be found even among care providers working with people with intellectual disabilities (Chapter 6). Therefore, even though more research is needed to make any firm conclusion, the findings of this thesis suggests that it may be relevant to raise awareness about the potential negative effects of passive harm in the form of paternalisation and neglect to create a sense of urgency to combat stigma, as well as a sense that it includes 'me' and not only 'others' who stigmatise.

Creating awareness and a positive culture and identity through self-advocacy groups

A strong way to create awareness about stigma, stereotypes, and discrimination, is the effort of self-advocacy groups, networks, and individuals. In addition to their function in awareness-raising, self-advocacy groups are generally seen as an important route to combat stigma and further social inclusion (Anderson & Bigby, 2016). Members of self-advocacy groups are involved in the development of national and regional policies concerning people with intellectual disabilities, are included in research funding bodies, and provide training and workshops for organisations (www.lfb.nl). In these situations, people can create awareness about stigma by sharing their experiences. Also, inclusive research has been proposed as a way to have the voices of people with intellectual disabilities heard (Milner & Frawley, 2018; Walmsley, 2004), and has the potential to promote change in policies and legislations (Johnson, Minogue, & Hopklins, 2014). As

demonstrated in Chapter 5 and 6, mainstream health professionals and care providers working in intellectual disabilities service organisations may unwittingly be a source of stigma. Self-advocates can provide training or education that might increase health professionals' and care providers' awareness of their own potentially stigmatising practices. For example, when self-advocates explain their feelings about a situation when health professionals talk to a care provider instead of to the person itself, this might raise awareness and change care practices. Self-advocates can follow training to learn how to effectively share common experiences (Verbrugge & Embregts, 2013). Similarly, self-advocates who are employed as co-researcher and co-lecturer can create awareness among students and researchers about their challenges through stigma.

Moreover, self-advocacy groups can be destigmatising in itself by empowering people (Fenn & Scior, 2019). The stereotypes that are held by the general public (Chapter 2 and 4), may lead to self-stigma and low self-esteem (Jahoda & Markova, 2004). People with intellectual disabilities can challenge stigma by learning to tell a positive narrative on the lives they lead, using their strengths and coping with their limitations. People with intellectual disabilities however, seem to lack a positive culture and identity (Spassiani & Friedman, 2014). This lack of a positive culture and identity is suggested to lead to people with intellectual disabilities dissociating themselves with others with intellectual disability in an attempt to cope with the stigma (Spassiani & Friedman, 2014). Several other minority groups tend to have a positive identity and culture, the culture of the deaf community is an inspiring case with strong leading examples who take pride in being deaf (e.g., Hamill & Stein, 2011). Self-advocacy groups can play a role in creating this positive identity (Mineur, Tideman, & Mallander, 2017), for example by enacting in the public space and sharing a positive narrative there. Moreover, self-authored spaces such as self-advocacy groups (i.e., places where people with intellectual disabilities come together to create communities and celebrate their individuality), can create a strong sense of belonging, friendships, and social connections with the wider community (Anderson & Bigby, 2016; Fenn & Scior, 2019; Mineur, Tideman, & Mallander, 2017).

An important policy implication here is that funding and policy support are essential to provide self-advocates with training and education, develop sustainable self-advocacy groups, and enable people with intellectual disabilities to be employed in self-advocate functions. Also, due to limitations in conceptual, adaptive, and social functioning, people with intellectual disabilities might need coaching to effectively function as a member of an advocacy group. Therefore, there need to be sufficient resources as well as an awareness about the relevance of advocacy groups; a willingness to listen to their stories and take them seriously. Thus, resources and support from policy and practice seem to be essential to enable advocacy groups to combat stigma and empower people with intellectual disabilities.

Public anti-stigma interventions: protest as essential ingredient

On a collective level, education, contact, and protest are the main strategies for combatting stigma (Kienhorst, Pijnenborg, & van Weeghel, 2016). Irrespective of the value of education and intergroup-contact, the findings of this thesis also seem to accord with the preliminary evidence that anti-stigma intervention concerning people with intellectual disabilities may especially benefit from adopting protest elements. Protest concerns the education of the general public about inequalities that are experienced by people with intellectual disabilities. For example, Walker and Scior added protest to their intervention by showing participants a documentary film in which a man with an intellectual disability experienced discrimination in seeking employment and was harassed and exploited by members of the general public (Walker & Scior, 2013). The findings of this thesis demonstrate the ambivalent nature of intellectual disabilities stigma. Ambivalent stigma may make it especially challenging for people with intellectual disabilities and their advocates to evaluate inequalities critically (Bergsieker et al., 2012). Also in real-life, people with intellectual disabilities seem to experience difficulties asserting their rights (e.g., Beart, Hardy, & Buchan, 2005). For example, people with intellectual disabilities continue to be of low priority in government policy and programs, and they often are not well represented in the disability rights movement (Scior et al., 2016). Policy is often focused on inclusion through deinstitutionalisation, however, if there are no employment opportunities, and there is segregated schooling and facilities, there is limited benefit from these policies (Woittiez et al., 2018). To take employment as an example, research suggests that people with intellectual disabilities experience participation in an integrated, competitive working environment as valuable, since it enables them to feel part of society, creates the possibility to make a meaningful contribution to society, and to be treated as equal. However, experiences of stigmatisation seem to hinder their wishes and actual opportunities to participate alongside people without intellectual disabilities (Voermans, Taminiau, Giesbers & Embregts, in press).

Therefore, protest components might make a valuable contribution to anti-stigma interventions with promising results for tackling stigmatisation towards people with intellectual disabilities (Seewooruttun & Scior, 2014; Walker & Scior, 2013). Protest, has been demonstrated to generate stronger emotional reactions and improvement in their support of empowerment and discouragement of sheltering than an intervention that focused on the similarity between people with and without intellectual disabilities (Walker & Scior, 2013). Yet, more research is needed about how and when protest can reduce stigma. For example, when protest involves telling the public not to hold negative views about a group, this can also have a paradoxical rebound effect and lead to an increase instead of decrease of stigma (Penn & Couture, 2002).

Implications for care providers: sharing power and expanding job function

Concerning care providers, there is limited evidence about the consecutives of raising of awareness about the relevance and impact of stigma regarding people with intellectual disabilities. As well, there is limited evidence regarding the effectiveness of stigma education. The question what might constitute effective elements of training that can reduce stigmatisation of care providers is hardly explored. Based on the results of this thesis we make two general suggestions regarding implications for care providers.

The first is that leads for future development of interventions can, reasonably, be derived from the general reference point that it takes power to stigmatise (Goffman, 1963; Link & Phelan, 2001). For example, people with intellectual disabilities in a supported living environment might engage in every aspect of stigma themselves in having stereotypes and negative feelings concerning their care providers (e.g., this one is a pusher, always wants something), and acting upon these stereotypes and feelings (e.g., avoiding them). However, care providers do not end up being a stigmatised group, simply because service users with intellectual disabilities do not have the social, economic, and political power to let care providers experience serious discriminatory consequences. There is an inevitable power difference that does exist in the relationship between a paid care provider and dependent service user. Therefore, care providers that are willing to share their power (e.g., by using shared-decision making) and to listen carefully to clients and their families/ network, might already act in a destigmatising manner (Douglas & Bigby, 2018; Giesbers et al., 2018; Pijnenborg, Kienhorst, van 't Veer, & van Weeghel, 2016).

Two specific examples that might enhance the deliberate and thoughtful sharing of power with people with intellectual disabilities can be found in (1) an approach of experience-based co-design (e.g. Bate & Robert, 2006), and (2) training staff in strategies of guided decision making. First, the approach of experience-based co-design facilitates the exchange of experiences between service users and care providers with the aim to improve the quality of services. Experience-based co-design and has been proven to be a feasible method in several settings (Haines et al., 2019). Second, as was found in this thesis in the results of the review study, care-providers themselves indicate their struggle in balancing between empowerment and sheltering of people with intellectual disabilities; also care providers mentioned themselves that they feel the tendency to (over-)protect people with intellectual disabilities which hampers sharing power. Therefore, paying attention in staff training in how to guide people with intellectual disabilities to make their own decisions might prove a forceful method to share power (Douglas & Bigby, 2018).

The second general note is that care providers might need to expand their views on their job responsibilities, and start to work by including the context of their clients within their job responsibilities. That is, although care providers play a major role in the lives of people with intellectual disabilities, it is far from evident that care providers play a role in advocating for people with intellectual disabilities. In the Netherlands, one of the key foci

within support is individualised support planning which is a legal requirement for service organizations as a way of enhancing person-centred support and high quality care. That is, people with intellectual disabilities together with their legal representatives/relatives and care providers should agree on goals for individual support along the lines of quality-of-life indicators (Herps, Buntinx, Schalock, Van Breukelen, & Curfs, 2016). However, such a strong focus on individual support planning, risks overlooking a structural line along which support workers are motivated to focus on the structural, societal context in which people with intellectual disabilities live. Moreover, it risks overlooking attention for how to advocate for their clients and challenge stigma. Furthermore, previous studies have shown that care providers' perceptions of a professional role identity primarily focused on care tasks and not on promoting social inclusion (Overmars-Marx, 2018). Therefore, care providers, working in intellectual disability services, may form a potential source of advocacy that is not fully used as this aspect of social care roles has not been recognised well. In addition to providing and arranging individualised support, care providers should be encouraged and facilitated to cooperate with local government and local communities to advocate for people with intellectual disabilities, increase familiarity, and combat existing stigma. Also, in training programs it seems to be relevant to pay attention to motivating support staff working in homes, day-care, or ambulant, to support encounters within mainstream society (e.g., providing them with good practices). Whenever possible, care providers should empower people with intellectual disabilities to play a role in this process of advocacy themselves. In the Dutch context this is needed both in the long-term intensive care context, as well as in the context of social support.

CONCLUDING REMARKS

People with intellectual disabilities are a diverse group of unique persons. However, they can be challenged by a collective stigma. As found in this thesis, within Western countries, the challenge of their stigma seems to lie in its ambivalent nature with a focus on dependency and incompetence, in limited opportunities, and neglect. The ambivalent nature of intellectual disabilities stigma might impede addressing inequalities, and limit wellbeing and opportunities in life. Continuing research is needed to unravel the complex process of stigma for people with intellectual disabilities. However, research cannot go without acting against stigma by supporting self-advocacy groups, protesting against inequalities, and empowering people with intellectual disabilities to reach valuable life goals and increase their wellbeing. Ultimately, stigma challenges us not to be ambivalent, but to fully want the other 'to be' (amo, volo ut sis).

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Addenda

Online Supplemental Material – Chapter 3

Summary

Samenvatting

Dankwoord (Aknowledgements)

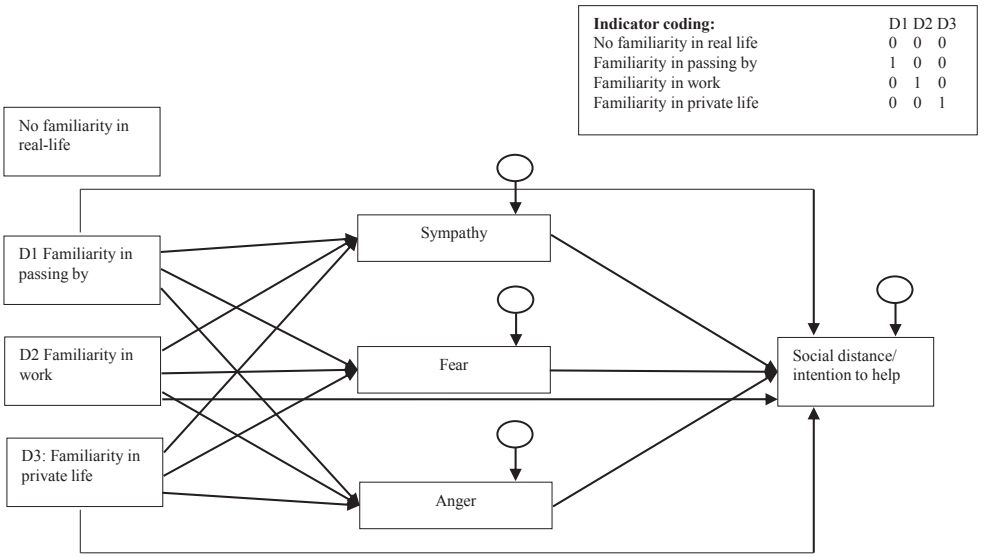
Curriculum vitae

Publications

SUPPLEMENTAL MATERIAL - ANALYSES CHAPTER 3

In this supplement you will find the model that we used to examine the relationship between familiarity and social distance/intention to help as mediated by emotions. We have used the strategy for mediation with a multicategorical predictor as proposed by Hayes & Preacher (2014). Graphical representation of the analysis as well as the syntax used in Mplus are included.

GRAPHICAL DISPLAY



SYNTAX USED IN MPLUS

```
Title:  Full mediation model social distance
Data: File is xxx.dat;

Variable:
  Names are
xxx

   USEVARIABLES ARE
   v6a v6h v6j  v6e v6i v6b v6c v6d v6f
   v7a_r v7b_r v7c_r v7d_r v7e_r
   Fam_rank_4cat d1 d2 d3;

 MISSING IS
  -999
```

```
!indicator coding
DEFINE:
if (Fam_rank_4cat eq 1) then d1 = 0;
if (Fam_rank_4cat eq 1) then d2 = 0;
if (Fam_rank_4cat eq 1) then d3 = 0;
if (Fam_rank_4cat eq 2) then d2 = 0;
if (Fam_rank_4cat eq 2) then d1 = 1;
if (Fam_rank_4cat eq 2) then d3 = 0;
if (Fam_rank_4cat eq 3) then d1 = 0;
if (Fam_rank_4cat eq 3) then d2 = 1;
if (Fam_rank_4cat eq 3) then d3 = 0;
if (Fam_rank_4cat eq 4) then d1 = 0;
if (Fam_rank_4cat eq 4) then d2 = 0;
if (Fam_rank_4cat eq 4) then d3 = 1;


!model definition
MODEL:
  sympathy BY v6e v6i v6b;
  fear BY v6a v6h v6j;
  anger BY  v6c v6d v6f;

   SOCDI BY v7a_r v7b_r v7c_r v7d_r v7e_r;
   v7b_r with v7c_r;

   fear ON d1 (a1);
   fear ON d2 (a2);
   fear ON d3 (a3);

   sympathy ON d1 (a12);
   sympathy ON d2 (a22);
   sympathy ON d3 (a32);

   anger ON d1 (a13);
   anger ON d2 (a23);
   anger ON d3 (a33);

   SOCDI ON fear (b);
   SOCDI ON sympathy (b2);
```

```
   SOCDI ON anger (b3);
   SOCDI ON   d1 (cp1);
   SOCDI ON   d2 (cp2);
   SOCDI ON   d3 (cp3);


!relative indirect effects;
MODEL INDIRECT:
   SOCDI IND fear d1;
   SOCDI IND fear d2;
   SOCDI IND fear d3;

   SOCDI IND sympathy d1;
   SOCDI IND sympathy d2;
   SOCDI IND sympathy d3;

   SOCDI IND anger d1;
   SOCDI IND anger d2;
   SOCDI IND anger d3;

MODEL CONSTRAINT:
   new (tot1 tot2 tot3 tot12 tot22 tot32 tot13 tot23 tot33);
   tot1=a1*b+cp1;
   tot2=a2*b+cp2;
   tot3=a3*b+cp3;

   tot12=a12*b2+cp1;
   tot22=a22*b2+cp2;
   tot32=a32*b2+cp3;

   tot13=a13*b3+cp1;
   tot23=a23*b3+cp2;
   tot33=a33*b3+cp3;

Analysis: Bootstrap = 1000;

OUTPUT:
  cinterval(bcbootstrap);
  RESIDUAL;
```

SUMMARY

The aim of this thesis was to expand knowledge about the process of stigma concerning people with intellectual disabilities, specifically by exploring the nature and level of stigma as found within the general public. Moreover, we addressed indications for stigma in two targeted groups within the general public: mainstream health professionals and care providers working in intellectual disability services.

CHAPTER 1

The first chapter provides a general introduction into the background of this study, the subject of stigma, and stigma in a context of social justice.

Societal background

People with intellectual disabilities do not only experience limitations in intellectual and adaptive functioning; they also experience many inequalities in daily life. Even in countries, such as the Netherlands, with relatively good resources, people with intellectual disabilities experience inequalities in for example monetary income, access to meaningful employment and access to mainstream healthcare, which impedes their participation in society. Stigmatisation is proposed as one of the main causes for this inequality that requires societal and political action.

The concept of stigma

Stigma refers to the experience of a devalued identity in a certain social context due to an attribute that is discounted. In this thesis we have examined the nature of this devaluation by following a social-psychological approach. Thereby we have focused on the general public's cognitive (stereotypes), emotional (prejudice) and behavioural (discrimination) response toward people with intellectual disabilities. A social-psychological approach mediates between psychological approaches (describing intrapsychic experiences of stigmatisation) and sociological approaches (describing processes on the level of society like norms and cultural rules and values).

Stigma and social justice

Research into stigma contains a paradoxical element in the fact that, to study stigma, we need to present people with intellectual disabilities as a group that is distinct from the general population (i.e., labelling). This can be considered as accentuating the stigma that we in fact want to address. Yet, in a context of social justice, labelling people with intellectual disabilities can be essential to provide them with different resources and to prevent discrimination. Thereby, it seems justified to use labelling as a means to explore stigma and its mechanisms.

Aims of the thesis

Only limited research has been conducted into the stigma of people with intellectual disabilities. Correspondingly, there is currently sparse input for anti-stigma interventions regarding people with intellectual disabilities. In this thesis we aimed to contribute to the understanding of the stigma; to explore 'what's in a label' when it concerns people with intellectual disabilities. In the first part of the thesis we have explored the nature and level of stigma that can be found within the Dutch general public. Thereby we have conducted a survey among a large representative sample of the Dutch general public. Also an exploratory small scale study was conducted. In the second part of the thesis we have focused on two targeted groups within the general population that can play a significant role in the lives of people with intellectual disabilities: mainstream health professionals and care providers working in intellectual disability services. We have examined indications for stigma toward people with intellectual disabilities in these targeted groups. That is, we have conducted systematic literature reviews into the nature of possible stigma.

Part 1: The Dutch general public's views about people with intellectual disabilities

In the first part of this thesis we thus aimed to draw a clearer picture of the Dutch general public's views about people with intellectual disabilities. This knowledge is essential for enhancing our understanding of stigma and developing effective anti-stigma interventions regarding people with intellectual disabilities. The results of a population survey are described in Chapters 2 and 3, the results of an exploratory study in Chapter 4.

CHAPTER 2

Within *Chapter 2* we have started by examining a fundamental cognitive aspect of stigma, namely the reported stereotypes regarding people with intellectual disabilities. Stereotypes refer to a specific set of characteristics that is assumed to exist among people with intellectual disabilities. Stereotypes can lead to prejudice and discrimination. Currently, within stigma research the question of the nature of this set of stereotypes for people with intellectual disabilities remains unsettled. In a mixed-method cross-sectional survey within a representative sample of the Dutch population ($n = 892$), participants were asked to rate their agreement (ranging from 1 = completely disagree to 5 = completely agree) about 18 statements describing people with intellectual disabilities; for example, "People with intellectual disabilities are happy". Moreover, in an open-ended question participants were asked to characterise people with intellectual disabilities. The list of stereotypes was based on previous research in the field of intellectual disabilities and the field of mental illness as well as a pilot study among the Dutch general public. We have demonstrated a set of three salient stereotypes (i.e., high score on the list of stereotypes and frequently described in the open question) concerning people with intellectual disabilities that represented both a positive and negative valence, namely: "friendly", "in need of help", and "unintelligent". "Nuisance" was not found to be a salient stereotype (i.e.,

low score on de list of stereotype and not frequently described in the open question) for people with intellectual disabilities. When asking participants in the open-ended question to describe people with intellectual disabilities, we found additional stereotypes that mainly referred to areas of dependence and incompetence; for example, being "less independent" "having low levels of social skills", and "having an impairment in thinking" were the most frequently reported. The stereotypes did not relate to high levels of explicit discrimination. Yet due to the both positive and negative valence of the stereotypes, subtle forms of discrimination may be expected such as limited opportunities for choice and self- determination. This may affect opportunities for participation and might be challenged by protest-components within anti-stigma efforts.

CHAPTER 3

Following the cognitive basis of stigma, the third chapter, using the same survey (n =892), focused on two additional aspects of stigma: familiarity and emotions. There is ample evidence that familiarity with a minority group reduces stigma (i.e., intergroup contact theory). Moreover, emotional reactions have been demonstrated to be foundational in the stigmatisation of minority groups and may elucidate why being less familiar with a minority group may relate to higher levels of stigma. In *Chapter 3* we have therefore focused on (1) the role of the general public's familiarity with people with intellectual disabilities in predicting stigma and (2) the mediating role of their emotions in the relationship between familiarity and discrimination. In this study, two thirds of the Dutch population sample did report to be familiar with people with intellectual disabilities in any form; one third did report to have no familiarity in real-life (i.e., at its best: participants indicated they saw a documentary about people with intellectual disabilities). Members of the general public who were unfamiliar with people with intellectual disabilities in real life, demonstrated higher levels of stigma on measures of attributions, emotions, and discriminatory intentions, than people who reported any form of real-life familiarity. Yet, when emotions (i.e., anger, fear, and sympathy) were taken into account, no direct effects of familiarity on levels of discrimination were found; emotions mediated this relationship. The emotion of fear was found to be the strongest mediator. That is, higher levels of familiarity with people with intellectual disabilities predicted lower levels of fear towards them, which in turn predicted lower levels of discrimination. The findings stress the continuing importance to advocate for people with intellectual disabilities to be recognised and become known within society. This increased familiarity might reduce stigma and increase positive experiences of inclusion. Support workers may have a vital role in this process. The importance of fear in the relationship between familiarity and discrimination may inform future research and anti-stigma interventions.

CHAPTER 4

Chapter 4, presents an exploratory study into stereotypes that extends Chapter 2 by examining which characteristics, according to the general public, do distinguish people with intellectual disabilities from the general public (i.e., stereotypes). In this study, we used a stratified convenience sample of the general public and a percentage technique to extend research with Likert-scales. Characteristics that most strongly distinguished people with intellectual disabilities from the general public (i.e., strongly stereotypical) involved areas of dependency and incompetence (e.g., 'have difficulty learning', 'are in need of help', 'are slow', 'are vulnerable'). Similarly, characteristics that were strongly counter-stereotypical (i.e., higher scores for the general public than for people with intellectual disabilities) concerned stereotypes of competence and independence (e.g., 'are independent', 'are able to work in a paid position'). Warm and friendly characteristics were found stereotypical but less prominent than the incompetent characteristics. Characteristics referring to people with intellectual disabilities as a nuisance were not (strongly) stereotypical. The strong focus on dependency and incompetence suggests that discrimination might be found in the context of justification theories whereby people belief that there are moral, ethical, legal, logical bases for their rejection.

Part 2: Indications of stigma among health professionals and care providers

The second part of the thesis, as described in Chapter 5 and 6, aimed to further explore stigma in the general public by targeting two subgroups that can have an important role in the wellbeing of people with intellectual disabilities, namely: mainstream health professionals, and care providers working in intellectual disability service organisations. These studies represent systematic literature reviews.

CHAPTER 5

Mainstream health professionals are members of the general public that play a paramount role in access to, and quality of mainstream healthcare for people with intellectual disabilities. They could hold specific stigmatising attitudes that need targeted interventions. In *Chapter 5* we have demonstrated, by the results of a systematic review (n =30 studies), that stigmatising attitudes towards people with intellectual disabilities can be found among mainstream health professionals in cognitions (e.g., knowledge, stereotypes), emotions (prejudice) and behaviour intentions (discrimination). Concerning cognitions, a lack of familiarity with and knowledge about people with intellectual disabilities was found. Moreover, people with intellectual disabilities were perceived as different compared to other patients, and as well as childlike, funny, strange or intimidating. Either low or unrealistic high expectations of the capabilities of people with intellectual disabilities were found. For example, breast cancer screening staff reported low expectations about peoples understanding and awareness of breast care, the ability

to self-examine and attendance for screening. Concerning emotions, health professionals reported stress, lack of confidence, fear, and anxiety in caring for people with intellectual disabilities. For example, general practitioners reported a lack of confidence in treating people with intellectual disabilities as a main issue leading to frustration. Concerning behavioural intentions, a tendency to treat people with intellectual disabilities differently from other patients and a lack of addressing autonomy of people with intellectual disabilities was reported. For example, there was a common misguided assumption among accident and emergency nurses that carers could consent to treatment and care on behalf of an adult with intellectual disabilities. In addition, mainstream health professionals were ambiguous in their willingness to change and adapt their daily-care practices to people with intellectual disabilities, such as adapting communication or allowing patients with more time. Thus, among mainstream health professionals there are clues for stigma and therefore cause to invest in anti-stigma interventions.

CHAPTER 6

Within *Chapter 6,* we have demonstrated, in a scoping review (n = 40 articles), that indications of public and structural stigma can be found amongst care providers working in intellectual disability service organisations. The included studies in this systematic scoping review were, mainly conducted in Western countries, and mostly not differentiating between levels of intellectual disabilities. Among all care providers involved in the lives of people with intellectual disabilities (e.g., therapists, psychologists, support staff), most studies focused on daily support staff. The majority of studies used self-report Likert-type measures of explicit attitudes and studies related to public stigma (i.e., cognitive, emotional, behavioural aspects of stigma) were scarce and mostly focused on cognitive aspects of stigma. Concerning indications of public stigma, two studies showed that care providers may stigmatise people with intellectual disabilities based on other social identities (e.g., in case of comorbidity, a person's personality disorder was found to be more strongly stigmatised than the person's intellectual disability). Indications were also found for support of structural stigma (i.e., social norms and policies that (un-)intentionally restrict opportunities for people). These studies mainly focused on aspects of community inclusion, and sexuality. There was scepticism regarding the feasibility of community inclusion for clients with high support needs. Care providers tended to be ambivalent about whether people with intellectual disabilities should be protected or empowered. Possible indications of stigmatisation regarding sexuality were found on issues related to parenthood, homosexual relationships, and priority of supporting sexuality, sexuality-related privacy, and self-determination. Furthermore, stigmatisation by care providers seemed to be related to subgroups of people with intellectual disabilities and appeared to be the strongest for people with severe/profound intellectual disabilities, and people with high support needs (e.g., people with challenging behaviour, or comorbid psychiatric

diagnoses). Finally, agreement of care providers with certain rights, such as (informed) decision-making, did not necessarily lead to care providers acting in accordance with such rights. Therefore, also among care providers clues for stigmatisation can be found that can affect the quality of support. Therefore addressing stigma within intellectual disability services organisations seems relevant.

CHAPTER 7: GENERAL DISCUSSION

In *Chapter 7* the findings of the thesis are discussed and suggestions for future research and practical implications are provided. Three main points are discussed that follow from the results of the thesis. First, in this thesis, the nature of intellectual disability stigma seems ambivalent (i.e., the stigma contains both a positive and negative valence). Low levels of discrimination were found when using common measures of discrimination with a clear negative valence. The ambivalent nature of stigma indicates that discrimination of people with intellectual disabilities might be found more clearly in passive harm (rather than active harm), neglect, and difficulties in addressing intergroup inequalities. The results of the systematic reviews align with this reasoning in the fact that very few explicitly harassing attitudes are found; but several indications of neglect and nonchalance that lead to discrimination are found. Thus, research and interventions might focus on and further examine this line of reasoning.

Second, especially for people with mild intellectual disabilities, real life experiences of stigma might not correspond to the general public's response to the label intellectual disabilities. The results of this thesis seems to indicate, in line with previous studies, that, when presented with the label 'intellectual disabilities', people do not seem to have in mind people with mild intellectual disabilities. Therefore, for people with mild intellectual disabilities, although they might not always be aware of it, disclosure of their intellectual disability might change people's response towards them. That is, when the intellectual disability goes unnoticed, people might me more negatively treated due to misattribution to other stigmatising causes that lead to more active harm; yet, being recognised as someone with an intellectual disability might lead to more passive harm (e.g., paternalisation, neglect, losing autonomy). Future research should address the relevance of disclosure for people with intellectual disabilities.

Third, the result of this thesis that a third of the general population does not report any real-life familiarity with people with intellectual disabilities, is remarkable given the high rate of community living of people with intellectual disabilities. Because higher levels of familiarity were related with lower levels of stigma, it seems essential in reducing stigma, to increase recognition of and familiarity with people with intellectual disabilities, and thereby reduce levels of fear towards people with intellectual disabilities.

Limitations and strengths

Concerning limitations and strengths of this thesis, a main strength is the use of a high quality population sample with a good response rate to study public stigma. Descriptive information on a population level is needed to develop evidence-based anti-stigma interventions. Limitations of this thesis concern the sole focus on direct self-report of stigma by the general public, the descriptive and cross-sectional nature of the studies, and the fact that several measures and concepts were borrowed from the field of mental illness, while during the course of the study it became clear that the nature of intellectual disabilities stigma is different from the nature of mental illness stigma and more specific measures could have been used. For example, 'nuisance' stereotypes were found not to be salient for people with intellectual disabilities, but these stereotypes are commonly assigned to people with mental illness or substance use disorders.

Future research

Future research should develop valid measurement instruments that are specific for the assessment of stigma regarding people with intellectual disabilities. To date, measurement scales have focused on attitudes rather than stigma, have been outdated, or borrowed from the field of mental illness where the nature of stigma is different. Furthermore future research should address a wider range of topics when addressing attitudes that support structural stigma. The topics that were mostly studied concerned community inclusion and sexuality, however, studies into, for example, attitudes towards employment, decision-making, or other relevant issues were scarce or missing.

Implications

Several practical implications can follow from the results of this thesis. Foremost, it is essential to raise awareness about the relevance of stigma in the lives of people with intellectual disabilities and its impact on their wellbeing. A strong way to create awareness about stigma, stereotypes, and discrimination, is the effort of self-advocacy groups, networks and individuals. Self-advocates can create awareness by sharing their experiences; and also empower people with intellectual disabilities by sharing a positive narrative, and providing a space of belonging and friendship. On a collective level, contact, education, and protest are main strategies for combatting stigma. The results of this thesis indicate that anti-stigma interventions may especially benefit from adopting protest elements. Protest concerns the education of the general public about inequalities that are experienced by people with intellectual disabilities. This seems to correspond to the ambivalent nature of intellectual disabilities stigma that can make addressing inequalities harder, and might lead to neglect and passive harm.

Care providers are having an important role in the lives of people with intellectual disabilities. Concerning these care providers, we have described two implications. First, following the general reference point that it takes power to stigmatise, care providers that

are willing and able to share power (e.g., by using shared-decision-making), and carefully listen to clients and their networks might already act in a destigmatising manner. Therefore, training staff in this regard is essential. Second, care providers in the Netherlands are working following the lines of individual support planning. However, there is a risk that the role of care providers in the structural and societal context is thereby minimized. Care providers view their professional role mostly in care tasks and not so much in promoting social inclusion. Therefore, care providers should be encouraged and facilitated to work with local government and communities in advocating for clients, combatting stigma, and increasing familiarity.

Conclusion

People with intellectual disabilities are a diverse group of unique persons. However, they can be challenged by a collective stigma. As found in this thesis, within Western countries, the challenge of their stigma seems to lie in its ambivalent nature with a focus on dependency and incompetence, in limited opportunities, and neglect. The ambivalent nature of intellectual disabilities stigma might impede addressing inequalities, and limit wellbeing and opportunities in life. Continuing research is needed to unravel the complex process of stigma for people with intellectual disabilities. However, research cannot go without acting against stigma by supporting self-advocacy groups, protesting against inequalities, and empowering people with intellectual disabilities to reach valuable life goals and increase their wellbeing. Ultimately, stigma challenges us not to be ambivalent, but to fully want the other 'to be'.

SAMENVATTING

Het onderzoek in dit proefschrift had als doel om de kennis die we hebben over het proces van stigmatisering bij mensen met een verstandelijke beperking te vergroten. We hebben ons daarbij gericht op de aard en de ernst van het stigma zoals we dit terugvinden in de algemene bevolking. Ook hebben we gekeken hoe we dit terugvinden bij twee specifieke groepen in de algemene bevolking, namelijk reguliere gezondheidszorg professionals, en zorgverleners in de gehandicaptenzorg.

HOOFDSTUK 1

Hoofdstuk 1 biedt een algemene introductie in de achtergrond van het onderzoek, het onderwerp stigma, en stigma in een context van sociale rechtvaardigheid.

Maatschappelijke achtergrond

Mensen met een verstandelijke beperking ervaren niet alleen beperkingen in adaptieve en intellectuele vaardigheden; ze ervaren vaak ook op veel manieren ongelijkheid in het dagelijks leven. Ook in landen als Nederland, waar er relatief goede ondersteuning en veel middelen beschikbaar zijn, ervaren mensen met een verstandelijke beperking ongelijkheid in, bijvoorbeeld, financiën, toegang tot zinvol werk, en toegang tot reguliere gezondheidszorg. Dit maakt het voor hen moeilijker om in het dagelijks leven mee te kunnen doen (sociale inclusie). Stigma wordt gezien als een van de belangrijkste oorzaken voor deze ongelijkheid en vraagt om een maatschappelijke en politieke respons.

Het concept stigma

Stigma verwijst naar de ervaring van een minderwaardige identiteit in een bepaalde sociale context als gevolg van een eigenschap (bv. verstandelijke beperking) die door de algemene bevolking als minder waard wordt gezien. We hebben in dit proefschrift onderzocht wat de aard is van deze minderwaardigheid; hoe kijken mensen uit de algemene bevolking naar mensen met een verstandelijke beperking (publiek stigma). We hebben dat gedaan aan de hand van een sociaalpsychologische benadering. Dat betekent dat we hebben gekeken naar cognities (stereotypen/beelden), emoties (vooroordelen), en gedrag (discriminatie) die in de algemene bevolking voorkomen als reactie op mensen met een verstandelijke beperking. Een sociaal-psychologische benadering is een middenweg tussen psychologische benaderingen (het beschrijven van intrapsychische ervaringen van stigma), en sociologische benaderingen (het beschrijven van processen op het niveau van een samenleving zoals normen en culturele waarden).

Stigma en sociale rechtvaardigheid

Onderzoek naar stigma heeft iets paradoxaals. Namelijk, om stigma te kunnen bestuderen moeten we mensen met een verstandelijke beperking onderscheiden als een groep van de algemene bevolking (labelen). Dit zou je kunnen zien als het benadrukken van het

stigma, terwijl we door het onderzoek een bijdrage willen leveren aan het verminderen van het stigma. Echter, vanuit het perspectief van sociale rechtvaardigheid is het labelen van mensen als een groep essentieel om hen de middelen te kunnen bieden die ze nodig hebben om volwaardig mee te kunnen doen in de maatschappij. Vanuit dit perspectief kan het labelen van mensen met een verstandelijke beperking als groep gerechtvaardigd worden; we gebruiken dit labelen immers om stigma-mechanismen te onderzoeken en daardoor stigma tegen te kunnen gaan.

Doelen van het onderzoek

Er is beperkt onderzoek gedaan naar het stigma van mensen met een verstandelijke beperking. Er is daardoor ook beperkte input voor anti-stigma interventies als het gaat om mensen met een verstandelijke beperking. Dit proefschrift had als doelstelling om ons begrip te vergroten van het stigma; om te verkennen 'what's in a label?' als het gaat over mensen met een verstandelijke beperking. In het eerste deel van dit proefschrift hebben we gekeken naar de aard en het niveau van stigma zoals we dat vinden onder de Nederlandse bevolking. Om dat te onderzoeken hebben we een vragenlijst afgenomen onder een grote representatieve steekproef van de Nederlandse bevolking. Daarnaast hebben we een verkennend kleinschalig onderzoek uitgevoerd. In het tweede deel van het proefschrift hebben we ons gericht op twee specifieke groepen binnen de algemene bevolking die vaak een belangrijke rol spelen in het leven van mensen met een verstandelijke beperking: reguliere gezondheidszorgprofessionals en zorgverleners die in de gehandicaptenzorg werken. Binnen deze twee groepen zochten we naar indicaties voor stigmatisering van mensen met een verstandelijke beperking in bestaand onderzoek; we hebben twee systematische literatuur onderzoeken uitgevoerd naar de aard van het mogelijke stigma in deze groepen.

Deel 1: De beelden die de Nederlandse bevolking heeft over mensen met een verstandelijke beperking.

In het eerste deel van dit proefschrift hebben we dus geprobeerd om de beelden die de Nederlandse bevolking heeft over mensen met een verstandelijke beperking in kaart te brengen. Deze kennis is essentieel om onze kennis van stigma te vergroten en effectieve anti-stigma interventies te kunnen ontwikkelen als het gaat over mensen met een verstandelijke beperking. De resultaten van dit populatie-onderzoek zijn beschreven in hoofdstuk 2 en 3, de resultaten van het verkennende, kleinschalige onderzoek zijn beschreven in hoofdstuk 4.

HOOFDSTUK 2

In *Hoofdstuk* 2 zijn we gestart met het onderzoeken van een fundamenteel cognitief aspect van stigma, namelijk de gerapporteerde stereotypen met betrekking tot mensen met een verstandelijke beperking. Stereotypen zijn een specifieke set van eigenschappen

waarvan men aanneemt dat die horen bij mensen met een verstandelijke beperking (bijvoorbeeld: lief, of langzaam). Stereotypen kunnen leiden tot vooroordelen en tot discriminatie. Tot nog toe was er nog weinig kennis over de stereotypen die er binnen de algemene Nederlandse bevolking heersen over mensen met een verstandelijke beperking. In een cross-sectioneel vragenlijst-onderzoek werd daarom een representatieve steekproef van de Nederlandse bevolking (*n* = 892) gevraagd om aan te geven bij een lijst van 18 eigenschappen in hoeverre deze eigenschappen passen bij mensen met een verstandelijke beperking (1 = helemaal oneens; 5 = helemaal eens). Daarnaast werden ze gevraagd om in een open vraag mensen met een verstandelijke beperking te typeren. De lijst van stereotypen die werd aangeboden was gebaseerd op voorgaand onderzoek naar stereotypen van verstandelijke beperkingen en psychiatrische aandoeningen, en een pilot studie onder de Nederlandse bevolking. Uit het onderzoek in dit proefschrift kwam een set van drie betekenisvolle stereotypen (NB hoge score op de lijst en frequent genoemd in de open vraag) over mensen met een verstandelijke beperking naar voren met zowel een positieve als een negatieve lading, namelijk: 'vriendelijk', 'hulpbehoevend', en 'niet intelligent'. 'Geven overlast', werd niet als een betekenisvol stereotype (NB lage score op de lijst en niet frequent genoemd in de open vraag) gezien voor mensen met een verstandelijke beperking. Op basis van de antwoorden die mensen gaven in de open vraag, vonden we aanvullende stereotypen die voornamelijk refereerden naar gebieden van afhankelijkheid en incompetentie; bijvoorbeeld, 'minder onafhankelijk', 'minder sociaal vaardig', en 'beperkt kunnen denken' werden het meest frequent genoemd. De stereotypen hingen niet samen met hoge niveaus van expliciete discriminatie. Door zowel de positieve als negatieve lading van de stereotypen verwachten we meer subtiele vormen van discriminatie zoals beperkte mogelijkheden voor het maken van keuzes en beslissingen. Dit kan de mogelijkheden voor participatie negatief beïnvloeden. Anti-stigma initiatieven die elementen van protest bevatten kunnen helpen om deze vormen van discriminatie tegen te gaan. Protest betreft het verwoorden en informeren over ongelijkheid die wordt ervaren door mensen met een verstandelijke beperking

HOOFDSTUK 3

Volgend op de cognitieve basis van stigma hebben we in het derde hoofdstuk met behulp van hetzelfde vragenlijst-onderzoek (*n* =892) ons gericht op twee aanvullende aspecten van stigma: bekendheid en emoties. Als het gaat om minderheidsgroepen in het algemeen heeft onderzoek al vele malen aangetoond dat bekendheid met een minderheidsgroep stigmatisering vermindert (intergroup contact theory). Daarnaast blijken emoties een fundamentele rol te spelen in stigmatisering van minderheidsgroepen. Inzicht in emoties kan daarom mogelijk verhelderen waarom minder bekendheid met een minderheidsgroep kan leiden tot hogere niveaus van stigma. Daarom hebben we ons in *Hoofdstuk 3* gericht op (1) de rol van de bekendheid van de Nederlandse bevolking met mensen met een verstandelijke beperking in het voorspellen van stigma, en (2) de mediërende rol die

emoties in de relatie tussen bekendheid en discriminatie zouden kunnen hebben. Wat we vonden is dat twee derde van de Nederlandse bevolking een vorm van bekendheid met mensen met een verstandelijke beperking rapporteert zoals mensen tegenkomen op straat, in de werkcontext of in de privé context; een derde rapporteerde geen bekendheid met mensen met een verstandelijke beperking in 'real-life'. De maximale bekendheid die deze deelnemers rapporteerden was dat ze een documentaire hebben gezien over mensen met een verstandelijke beperking. Mensen uit de algemene bevolking die geen bekendheid in real-life met mensen met een verstandelijke beperking rapporteerden, scoorden hogere niveaus van stigma op maten als attributies, emoties en discriminerende intenties dan mensen die wel een vorm van real-life bekendheid rapporteerden. Echter, wanneer emoties (boosheid, angst, en sympathie) werden meegenomen en de analyses, werden er geen directe effecten meer gevonden van bekendheid op niveaus van discriminatie; emoties medieerden dit effect. De emotie angst was de sterkste mediator. Dat betekent dat meer bekendheid met mensen met een verstandelijke beperking samenhing met minder angst ten opzichte van hen, wat vervolgens samenhangt met minder discriminatie. Deze bevindingen benadrukken het blijvende belang van het streven naar herkenning en erkenning van mensen met een verstandelijke beperking in de samenleving. Een verhoogde bekendheid zou angst en stigma kunnen verminderen en kunnen leiden tot meer positieve ervaringen van sociale inclusie. De invloed van de emotie angst op de relatie tussen bekendheid en discriminatie is van belang voor toekomstig onderzoek en voor anti-stigma interventies.

HOOFDSTUK 4

Hoofdstuk 4 bevat, als een uitbreiding op hoofdstuk 2, een verkennend onderzoek naar stereotypen waarbij we hebben onderzocht welke eigenschappen mensen met een verstandelijke beperking onderscheiden van de algemene bevolking (volgens mensen uit die algemene bevolking). In dit onderzoek hebben we een gestratificeerde gemaks-steekproef van de algemene bevolking gebruikt en een percentage techniek. Dat betekent dat we deelnemers aan het onderzoek hebben gevraagd hoeveel procent van de mensen met een verstandelijke beperking een bepaalde eigenschap hebben (bv. 80% van de mensen met een verstandelijke beperking is vriendelijk); en hoeveel procent van de mensen uit de algemene bevolking diezelfde eigenschap hebben (bv. 70% van de mensen uit de algemene bevolking is vriendelijk). Eigenschappen gerelateerd aan afhankelijkheid en incompetentie (bijv. 'kunnen moeilijk leren', 'hulpbehoevend', 'sloom', 'kwetsbaar') werden gerapporteerd als het meest sterk onderscheidend voor mensen met een verstandelijke beperking ten opzichte van de algemene bevolking (hoog percentage mensen met een verstandelijke beperking hebben deze eigenschappen en een laag percentage mensen uit de algemene bevolking). Conform deze uitkomst waren eigenschappen gerelateerd aan competentie en onafhankelijkheid (bijv. 'onafhankelijk', 'in staat betaald werk te verrichten') meer van toepassing bevonden op de algemene bevolking dan op mensen

met een verstandelijke beperking. Warme en vriendelijke eigenschappen waren wel stereotiep maar minder sterk dan de incompetente eigenschappen. Eigenschappen die verwezen naar overlast werden niet (sterk) stereotiep gevonden voor mensen met een verstandelijke beperking. De sterke focus op afhankelijkheid en incompetentie suggereert dat discriminatie gevonden zou kunnen worden in een context van rechtvaardigingstheorieën, waarbij mensen geloven dat er morele, ethische, juridische, of logische gronden bestaan voor discriminatie.

Deel 2: aanwijzingen voor stigma onder gezondheidszorgprofessionals en zorgverleners
In het tweede deel van dit proefschrift, zoals beschreven in hoofdstuk 5 en 6, onderzoeken we stigma in de algemene bevolking verder door te focussen op twee subgroepen die een belangrijke rol kunnen spelen in het welzijn van mensen met een verstandelijke beperking, namelijk: reguliere gezondheidszorgprofessionals en zorgverleners die werken binnen gehandicaptenzorg organisaties. Deze onderzoeken zijn systematische literatuur onderzoeken.

HOOFDSTUK 5

Reguliere gezondheidszorgprofessionals zijn een onderdeel van de algemene bevolking. Deze professionals kunnen een belangrijke rol kan spelen in de toegang tot, en de kwaliteit van reguliere gezondheidszorg voor mensen met een verstandelijke beperking. Er kan sprake zijn van specifieke stigmatiserende attitudes die vragen om gerichte interventies. In *Hoofdstuk 5* laten de resultaten van een systematische review (n = 30 onderzoeken) zien dat stigmatiserende attitudes kunnen worden gevonden onder reguliere gezondheidszorgprofessionals in cognities (bijv. kennis, stereotypen), emoties (vooroordelen), en gedragsintenties (discriminatie). Wat betreft cognities wordt er een gebrek aan bekendheid met en kennis over mensen met een verstandelijke beperking gevonden. Ook worden mensen met een verstandelijke beperking gezien als anders dan andere patiënten, soms als kinderlijk, grappig, raar, of intimiderend. Zowel lage als onrealistisch hoge verwachtingen wat betreft de capaciteiten van mensen met een verstandelijke beperking worden gerapporteerd. Zo rapporteerden zorgprofessionals die borstkanker-screenings uitvoeren lage verwachtingen van het begrip en besef van borstkanker van mensen met een verstandelijke beperking, en een lage verwachting van de mogelijkheden om zichzelf te onderzoeken en naar de screening te komen. Wat betreft emoties rapporteren gezondheidszorgprofessionals stress, onzekerheid en angst in het zorgen voor mensen met een verstandelijke beperking. Huisartsen rapporteerden bijvoorbeeld dat onzekerheid in het behandelen van mensen met een verstandelijke beperking een belangrijk punt is wat ook leidt tot frustratie. Wat betreft gedragsintenties is er een neiging om mensen met een verstandelijke beperking anders te behandelen dan andere patiënten. Ook werd een gebrekkige ondersteuning van de autonomie van mensen met een verstandelijke beperking gerapporteerd. Onder eerste-hulpverpleegkundigen

bestond bijvoorbeeld de (verkeerde) aanname dat begeleiders en verzorgers namens mensen met een verstandelijke beperking toestemming mogen geven voor behandeling en zorg. Daarnaast waren reguliere gezondheidszorgprofessionals niet duidelijk bereid om hun dagelijkse werkwijze aan te passen aan mensen met een verstandelijke beperking, zoals bijvoorbeeld het aanpassen van communicatie of patiënten meer tijd bieden. Concluderend zijn er in dit onderzoekaanwijzingen gevonden voor stigma onder reguliere gezondheidszorgprofessionals en is investeren in anti-stigma interventies gericht op deze groep zorgprofessionals belangrijk om mensen een verstandelijke beperking de toegang tot goede kwaliteit gezondheidszorg te bieden.

HOOFDSTUK 6

In *hoofdstuk 6* laten we door middel van een systematische scoping review (*n* = 40 artikelen) zien dat indicaties voor publiek stigma en steun voor structureel stigma (NB structureel stigma verwijst naar sociale normen en beleid dat (on)opzettelijk de mogelijkheden van mensen beperkt) kunnen worden gevonden onder zorgprofessionals binnen de gehandicaptenzorg. De onderzoeken die in de review werden geïncludeerd waren voornamelijk uitgevoerd in Westerse landen, en maakten meestal geen onderscheid tussen de verschillende niveaus van verstandelijke beperkingen. Van alle zorgprofessionals die betrokken zijn in het leven van mensen met een verstandelijke beperking (bv. Logopedisten, psychologen, begeleiders), richtten de meeste onderzoeken zich op dagelijkse begeleiders. De meeste onderzoeken gebruikten zelfrapportage van directe attitudes met behulp van Likert-schalen; er waren weinig onderzoeken met betrekking tot publiek stigma, die weinige onderzoeken richten zich voornamelijk op cognitieve aspecten van stigma. Met betrekking tot publiek stigma lieten twee onderzoeken zien dat begeleiders mensen met een verstandelijke beperking ook kunnen stigmatiseren op basis van andere kenmerken dan de verstandelijke beperking (bijvoorbeeld, in het geval van bijkomende psychiatrische problematiek leek een persoonlijkheidsstoornis meer stigmatiserende reacties op te roepen dan de verstandelijke beperking van die persoon). Er werden ook aanwijzingen gevonden voor steun aan structureel stigma onder begeleiders. Deze onderzoeken naar structureel stigma richtten zich op aspecten van sociale inclusie en seksualiteit. Er werd scepsis gerapporteerd ten aanzien van de haalbaarheid van inclusie voor mensen met een grote ondersteuningsbehoefte. Zorgverleners rapporteerden een ambivalente houding ten opzichte van de vraag of mensen met een verstandelijke beperking versterkt of beschermd moeten worden. Indicaties voor stigma ten aanzien van seksualiteit werden gevonden op specifieke thema's als ouderschap, homoseksuele relaties, de prioriteit voor het ondersteunen van seksualiteit, privacy met betrekking tot seksualiteit en zelfbepaling. Steun voor structureel stigma door begeleiders leek gerelateerd te zijn aan bepaalde subgroepen van mensen met een verstandelijke beperking en leek het sterkst met betrekking tot mensen met een ernstige of zeer ernstige verstandelijke beperking, en mensen met een grote ondersteuningsvraag (bv.

Mensen met moeilijk verstaanbaar gedrag of bijkomende psychiatrische problematiek). Tot slot bleek dat hoewel zorgprofessionals achter bepaalde rechten van mensen met een verstandelijke beperking stonden, zoals (geïnformeerd) beslissingen maken, dit niet altijd leidde tot gedrag wat past bij deze rechten. Concluderend, ook onder zorgprofessionals in de gehandicaptenzorg werden indicaties voor stigma gevonden die de kwaliteit van zorg negatief kunnen beïnvloeden. Daarom lijkt het belangrijk dat er binnen de gehandicaptenzorg ook aandacht is voor stigma binnen de eigen organisatie.

HOOFDSTUK 7: ALGEMENE DISCUSSIE

Hoofdstuk 7 beschrijft de discussie van de resultaten van dit proefschrift, suggesties voor vervolgonderzoek en praktische implicaties. We bespreken drie belangrijke punten die volgden uit de resultaten van dit proefschrift. Het eerste is dat, in dit proefschrift, de aard van het stigma van verstandelijke beperkingen ambivalent lijkt; het stigma kent zowel aspecten met een positieve als een negatieve waarde. We vonden bijvoorbeeld lage niveaus van expliciete discriminatie en we vonden zowel positieve als negatieve stereotypen. Deze ambivalente aard van het stigma wijst erop dat discriminatie van mensen met een verstandelijke beperking mogelijk eerder kan worden gevonden in passieve/subtiele schade (in plaats van actieve schade). Passieve schade voor mensen met een verstandelijke beperking kan bijvoorbeeld zichtbaar worden in het negeren van hun behoeften en moeite in het aankaarten van ongelijkheid. De resultaten van de systematische reviews ondersteunen deze denkrichting: er werden weinig expliciet negatieve/vijandige attitudes gevonden en tegelijkertijd werden er wel aanwijzingen gevonden voor het negeren van behoeftes, of nonchalance wat kan leiden tot discriminatie. Onderzoek en interventies zouden zich kunnen richten op het verder onderzoeken van deze lijn van redeneren.

Ten tweede kunnen ervaringen van stigma in het dagelijks leven voor mensen met een lichte verstandelijke beperking anders zijn dan men zou verwachten op basis van de reactie van het algemene bevolking op het label verstandelijke beperking. De resultaten van dit onderzoek wijzen erop, in lijn met voorgaand onderzoek, dat wanneer mensen uit de algemene bevolking reageren op het label verstandelijke beperking, ze daarbij niet denken aan mensen met een lichte verstandelijke beperking. Openheid geven over je verstandelijke beperking kan voor mensen met een lichte verstandelijke beperking een verschil maken in de reactie die mensen op hen hebben. Wanneer de verstandelijke beperking niet wordt opgemerkt worden mensen wellicht negatiever behandeld omdat hun gedrag wordt gekoppeld aan andere stigmatiserende oorzaken die tot meer actieve schade leiden. Van de andere kant kan het herkend worden als iemand met een verstandelijke beperking leiden tot meer passieve schade (bijv. paternalisering, negeren van behoeftes, verliezen van autonomie). Toekomstig onderzoek zou de relevantie van dit dilemma voor mensen met een lichte verstandelijke beperking verder moeten onderzoeken.

Ten derde laten we in dit proefschrift zien dat een derde van de algemene bevolking geen real-life bekendheid met mensen met een verstandelijke beperking rapporteert. Dit is opmerkelijk gezien het feit dat een groot deel van de mensen met een verstandelijke beperking in reguliere woonwijken woont. Meer bekendheid met mensen met een verstandelijke beperking was gerelateerd aan lagere niveaus van stigma. Om stigma te verminderen lijkt het daarom essentieel dat mensen met een verstandelijke beperking meer herkend worden en meer bekend worden; mogelijk wordt daarmee de angst ten opzichte van deze doelgroep minder en daarmee ook discriminerende uitkomsten.

Sterke kanten en beperkingen van het onderzoek

Wat betreft de sterke kanten en de beperkingen van het onderzoek in dit proefschrift is een belangrijk sterk punt het gebruik van een hoge kwaliteit populatiesteekproef met een goede respons. Beschrijvende informatie op populatieniveau is nodig om anti-stigma interventies goed te kunnen onderbouwen. Beperkingen van dit onderzoek betreffen de beperkte focus op zelfrapportage van stigma bij de algemene bevolking, de beschrijvende en cross-sectionele aard van de onderzoeken, en het feit dat verschillende meetinstrumenten en concepten zijn geleend vanuit de psychiatrie, terwijl tijdens het onderzoek bleek dat de aard van het stigma van psychiatrische aandoeningen anders is dan de aard van stigma van mensen met een verstandelijke beperking. Bijvoorbeeld, het stereotype 'geven overlast' is sterk aanwezig en bepalend bij stigmatisering van psychiatrische aandoeningen, maar niet bij mensen met een verstandelijke beperking.

Toekomstig onderzoek

Toekomstig onderzoek is nodig om valide meetinstrumenten te ontwikkelen die specifiek zijn voor het meten van stigma ten opzichte van mensen met een verstandelijke beperking. Tot nu toe zijn meetinstrumenten veelal gericht op attitudes en niet op stigma, zijn ze verouderd, of geleend vanuit de psychiatrie waar de aard van het stigma anders is. Wanneer het gaat over de steun van structureel stigma, zou toekomstig onderzoek zich moeten richten op een bredere scope van onderwerpen. De onderwerpen die veel bestudeerd werden waren sociale inclusie en seksualiteit. Onderzoeken naar attitudes ten opzichte van bijvoorbeeld werk, het maken van beslissingen, of andere relevante onderwerpen waren schaars of volledig afwezig.

Implicaties

Verschillende praktische implicaties volgen uit de resultaten van dit proefschrift. Allereerst is het essentieel dat mensen zich bewust zijn van de relevantie van stigma in het leven van mensen met een verstandelijke beperking en van de impact die stigma kan hebben op hun welzijn. Het opkomen voor het eigen belang door mensen met een verstandelijke beperking zelf, in de vorm van belangenorganisaties, netwerken, en individuele ervaringsdeskundigen, is een sterke manier om bewustzijn te creëren omtrent stigma, stereotypen en discriminatie. Self-advocates (ervaringsdeskundigen die opkomen voor

de belangen van mensen met een verstandelijke beperking) kunnen bewustzijn creëren door hun ervaringen te delen. Ook kunnen ze mensen met een verstandelijke beperking sterker maken door een positief rolmodel te zijn met een eerlijk levensverhaal. Daarnaast kunnen groepen van self-advocates een plek zijn waar een gevoel van erbij horen en vriendschap een plek heeft. Op collectief niveau zijn contact (bekendheid), onderwijs en protest de drie belangrijkste strategieën om stigma tegen te gaan. De resultaten van dit proefschrift wijzen erop dat anti-stigma interventies in het bijzonder baat kunnen hebben bij het opnemen van elementen van protest in de interventies. Protest betreft het verwoorden en informeren over ongelijkheid die wordt ervaren door mensen met een verstandelijke beperking. Dit sluit aan bij de ambivalente aard van het stigma van mensen met een verstandelijke beperking, wat het moeilijke maakt om ongelijkheid aan te kaarten, en kan leiden tot het negeren van behoeften en passieve schade.

Zorgprofessionals spelen vaak een belangrijke rol in het leven van mensen met een verstandelijke beperking. Met betrekking tot zorgprofessionals hebben we twee implicaties besproken. Als eerste, wanneer we het algemene uitgangspunt volgen dat stigmatisering alleen kan plaatsvinden in een kader van machtsongelijkheid, is het belangrijk dat zorgprofessionals in staat zijn en gemotiveerd om macht te delen (bv. Door 'shared-decision-making). Door zorgvuldig te luisteren naar cliënten en hun netwerk, kunnen zorgprofessionals al op een de-stigmatiserende manier werken. Het is daarom essentieel dat zorgprofessionals ook ondersteund worden om een dergelijke houding te ontwikkelen of te vergroten. Ten tweede, zorgverleners in Nederland werken volgens individuele ondersteuningsplannen om zoveel mogelijk persoons-gerichte zorg te bieden met individuele doelen volgens kwaliteit van leven domeinen. Het risico bestaat echter dat, met de focus op individuele doelen de rol van zorgprofessionals in de structurele en sociale context wordt geminimaliseerd. Zorgprofessionals zien hun professionele rol dan ook voornamelijk in zorgtaken en niet zo zeer in het bevorderen van sociale inclusie. Zorgprofessionals zouden moeten worden gefaciliteerd en aangemoedigd, in aanvulling op de persoonsgerichte, individuele zorg en doelen, samen te werken met plaatselijke gemeentes en gemeenschappen (de structurele en sociale context) om voor cliënten op te komen, stigma te bestrijden, en de bekendheid van mensen te vergroten.

Conclusie

Mensen met een verstandelijke beperking vormen een diverse groep van unieke personen. Tegelijkertijd ervaren ze als groep de uitdaging van een collectief stigma. In dit proefschrift lieten we zien dat, in Westerse landen, de uitdaging van het stigma lijkt te liggen in de ambivalente aard van het stigma met een focus op afhankelijkheid, incompetentie, ingeperkte mogelijkheden en het negeren van behoeften. De ambivalente aard van het stigma van een verstandelijke beperking kan het moeilijker maken om ongelijkheid aan te kaarten, en kan het welzijn van mensen en de kansen die ze krijgen verminderen. Er blijft onderzoek nodig om het complexe proces van stigma voor mensen

met een verstandelijke beperking te ontrafelen. Onderzoek naar stigma kan niet gedaan worden zonder dat er tegelijkertijd aandacht is voor het bestrijden van stigma, door het ondersteunen van belangenorganisaties (self-advocacy-groups), het aankaarten van ongelijkheid, en het versterken van mensen met een verstandelijke beperking om de voor hen belangrijke doelen in hun leven te behalen en zo hun welzijn te vergroten. Uiteindelijk stelt stigma ons voor de uitdaging om niet ambivalent te zijn, maar te willen dat de ander volledig 'kan zijn'.

DANKWOORD

We meet no ordinary people in our lives.
-- C.S. Lewis, The weight of glory

Tijdens een promotietraject zijn er veel mensen die daar, soms bewust, soms onbewust een bijdrage aan leveren. Dit woord van dank gebruik ik graag om mijn waardering daarvoor uit te spreken. Als eerste ben ik Dichterbij erkentelijk voor het mogelijk maken van dit promotietraject. Een investering in onderzoek dat niet morgen al iets oplevert, maar wel een bijdrage kan leveren aan kwaliteit en visie op de zorg. Bedankt voor het mogelijk maken daarvan.

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CURRICULUM VITAE

Hannah Pelleboer-Gunnink was born on the 16th of February 1988, in Nieuwerkerk aan den IJssel, the Netherlands. After growing up in the town of Hoogeveen, she enrolled at Utrecht University to study the Bachelor programs 'Clinical and Health Psychology', and 'Ortho-pedagogical Sciences'. She then began the research master 'Development and Socialisation in Adolescence and Childhood' (DaSCA), which she combined with the clinical masters program 'Ortho-pedagogics', the Intellectual Disabilities track. During the clinical master program she did an internship as care coordinator in a primary school / care organisation for children with neuro-motoric limitations (Dominiek Savio Institute) in Belgium. During the research master program she had an internship at the research department of Curium-LUMC in Leiden, academic center for child and youth psychiatry. During her studies she worked as a lecturer of methods and statistics for freshman students. Also she worked as support staff with people with an intellectual disability within a community group home. In September 2013 she started as a PhD candidate investigating the topic of stigmatization of people with intellectual disabilities. The research project was funded by Stichting Dichterbij (a service organisation for people with intellectual disabilities) and performed at the Scientific Center for Care and Welfare (Tranzo). In January 2019 Hannah started to work as a care coordinator (psychologist) at Stichting Dichterbij.

Hannah Pelleboer-Gunnink is geboren op 16 februari 1988 in Nieuwerkerk aan den IJssel. Ze is opgegroeid in Hoogeveen en heeft daarna aan de Universiteit van Utrecht de bachelor programma's 'klinische en gezondheidspsychologie' en 'pedagogische wetenschappen' gevolgd. Vervolgens heeft ze de onderzoeks-master 'Development and Socialisation in Adolescence and Childhood' (DaSCA) gecombineerd met het klinische masterprogramma 'Orthopedagogiek', richting 'gehandicaptenzorg'. Tijdens de klinische master heeft ze een stage gelopen als zorgcoördinator bij een organisatie voor onderwijs en zorg voor mensen met een neuro-motorische beperking (afdeling primair onderwijs, Dominiek Savio Instituut) in België. Tijdens de onderzoeks-master heeft ze een stage gelopen bij het onderzoeks-departement van het Curium-LUMC in Leiden, academisch centrum voor kinder- en jeugdpsychiatrie. Tijdens haar studie heeft ze gewerkt als docent methoden, technieken en statistiek voor eerstejaars studenten. Ook heeft ze als begeleider gewerkt in de zorg voor mensen met een verstandelijke beperking op drie verschillende woongroepen. In september 2013 is ze gestart als PhD-student op het onderzoek naar stigmatisering van mensen met een verstandelijke beperking. Het onderzoeksproject is gefinancierd door stichting Dichterbij, een organisatie voor zorg en hulpverlening aan mensen met een verstandelijke beperking, en uitgevoerd bij Tranzo, wetenschappelijk centrum voor zorg en welzijn. In januari 2019 is ze gaan werken regiebehandelaar/ orthopedagoog bij stichting Dichterbij.

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